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Managing the long term health consequences of COVID-19 in Australia

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List of Abbreviations

Abbreviation	Definition
ANZCTR	Australian New Zealand Clinical Trials Registry
ASCOT-ADAPT	Australasian COVID-19 Trial Adaptive Platform Trial
C19-YRS	COVID-19 Yorkshire Rehabilitation Screen
CDC	Centers for Disease Control and Prevention (US)
CFS	Chronic fatigue syndrome
CHIKV	Chikungunya virus infection
DALY	Disability Adjusted Life Years
EQ-5D	EuroQol- 5 Dimension
EVD	Ebola Virus disease
EXPH	Expert Panel on effective ways of investing in health
HIV/AIDS	Human immunodeficiency virus, acquired immunodeficiency syndrome
ICD	International Classification of Diseases
ICHOM	The International Consortium for Health Outcomes Measurement
ICN	International Council of Nurses
IPU	Integrated Practice Unit
MBS	Medicare Benefits Schedule
MDT	Multi-Disciplinary Team
ME	Myalgic Encephalomyelitis
MERS	Middle East Respiratory Syndrome
MIS-C	Multisystem Inflammatory Syndrome in Children
MRFF	Medical Research Future Fund
NAM	National Academy of Medicine
NCCET	National COVID-19 Clinical Evidence Taskforce
NCHRAC	National COVID-19 Health Research Advisory Committee
NHMRC	National Health and Medical Research Council
NICE	National Institute for Health and Care Excellence
ONS	Office for National Statistics
PBS	Pharmaceutical Benefits Scheme
PCR	Polymerase Chain Reaction
PEM	Post-exertional malaise
PICS	Post-intensive care syndrome
PIMS	Paediatric Inflammatory Multisystem Syndrome
PROMs	Patient Reported Outcome Measures
PTSD	Post-traumatic stress disorder
PVFS	Post Viral Fatigue Syndrome
PVS	Post Viral Fatigue
QALY	Quality-Adjusted Life-Year
RNA	Ribonucleic Acid
SARS	Severe Acute Respiratory Syndrome
SF	Medical Outcomes Study 36-Item Short-Form Health Survey
SIGN	Scottish Intercollegiate Guidelines Network
VBHC	Value-based healthcare

key messages

- Primary prevention of COVID-19 should be prioritised as the most effective means of mitigating the long-term health consequence of infection at population level. However plans must be put in place to allow rapid scaling-up of long-term care were COVID-19 control measures to fail.
- In Australia, the immediate urgency of responding to the COVID-19 pandemic and the pressing need to respond operationally has moved attention away from health system reform. This situation will not persist indefinitely, and Australian governments should now consider an effective and proportionate value -based response to COVID-19, and its longer-term health consequences, that considers patient health outcomes and costs.
- Although estimated case numbers in Australia are low, the emergence of Long COVID provides an opportunity to implement new approaches to integrated, well-coordinated, multidisciplinary, person centred care. This will require health care professions to be supported to work at the top of their scope of practice and should occur through:
    - a national post-COVID Centre of Excellence and state-based care coordination centres;
    - a nationwide COVID-19 data registry that combines patient-level data on COVID-19 and subsequent health and healthcare utilisation history;
    - commissioned research and modelling on the morbidity burden of Long COVID and post-COVID sequelae in different age and population groups that supplements emerging data on the mortality burden of COVID-19 and associated control measures;
    - the development of regular, updated clinical guidelines that reflect evolving evidence on the long-term management of post-COVID care; and
    - MBS and PBS benefits that adequately support patients living with Long COVID or other sequelae and other “safety net” measures put in place to mitigate out-of-pocket costs for chronic disease management to support these patients fully.
- The Australian and state and territory governments should consider the long-term care consequences of COVID and its associated additional cost burden in resource allocation and risk management decision processes in parallel with COVID-19 control strategy policies.
- Support should also be provided for research that focuses on health policy, health economics, social determinants and more directly on the effect of COVID-19 on the structure and function of the health system.

executive summary

To date, Australia is one of a group of countries who have succeeded in limiting and largely controlling the spread of COVID-19 within their borders. As a result of these effective control measures, Australia has suffered a much lower burden of COVID-19 disease than most other countries; with rates of infections and deaths being an order of magnitude lower than those seen in most other high-income nations.

However, in those countries which have suffered more severely than Australia, concerns about the long-term consequences of the pandemic are increasingly focused on the long-term clinical sequelae being seen in survivors of COVID-19, including Long COVID and a wide range of other conditions.

Although Long COVID is not yet fully understood, health policy makers, including those in Australia, should be preparing to address it.

This policy challenge is exacerbated precisely because COVID-19 cases in Australia have been low. As of April 2021, the estimated likely case numbers for Long COVID lie between 2,867 and 5,413 cases. Therefore, the Australian response to Long COVID needs to be proportionate - suitable for dealing with today's relatively small numbers, yet capable of rapid scaling-up if circumstances required it.

An outcome focused, value-based health care approach that reflects contemporary governance and funding arrangements, and that can achieve effective management of Long COVID, provides a useful template for a national strategy for managing the long-term sequelae of COVID-19. This should consider 1) a nationally unified and regionally controlled health system that puts patients at the centre, 2) performance information and reporting that is fit for purpose, 3) an integrated health workforce that exists to serve and meet population health needs, and 4) funding that is sustainable and appropriate to support a high-quality health system.

Against this framework, governments will need to consider the potential clinical evolution of patients who may have suffered organ damage and impairment due to COVID-19, while balancing the competing risks of inaction and overdiagnosis; in addition to preparing proportionately for the possible emergence of other as yet unknown, post-COVID sequelae, especially neurological conditions, such as those seen after other viral pandemics.

Recommendations are also provided to support:

- the establishment of a national post-COVID Centre of Excellence and state-based care coordination centres;
- a nationwide COVID-19 data registry that combines patient-level data on COVID-19 and subsequent health and healthcare utilisation history;

- commissioned research and modelling on the morbidity burden of Long COVID and post-COVID sequelae in different age and population groups that supplements emerging data on the mortality burden of COVID-19 and associated control measures;
- the development of regular, updated clinical guidelines that reflect evolving evidence on the long-term management of post-COVID care; and
- MBS and PBS benefits that adequately support patients living with Long COVID or other sequelae and other "safety net" measures put in place to mitigate out-of-pocket costs for chronic disease management to support these patients fully.

Effective clinical and social support for COVID-19 survivors is essential – but the best way to minimise the long-term burden of COVID-19 on the Australian population remains preventing SARS-CoV-2 from gaining a foothold here.

1 Introduction

1.1 Short and long-term consequences of COVID-19 for health systems

The COVID-19 pandemic continues to exert an extraordinary and pervasive impact on societies, economies and health systems across the world. Its direct morbidity and mortality impacts march onwards, with over 164 million cases and more than 3.4 million deaths worldwide as of 20th May 2021 (Dong, Du & Gardner 2020).

COVID-19 has profoundly impacted health care systems across the globe. All health systems have been required to pivot rapidly to ramp up public health measures, testing and contact tracing, and more recently – in most wealthy nations at least – to deliver mass vaccination campaigns.

Infection control measures, social distancing and government-mandated lockdowns, and changes in patient behaviour have had rapid and dramatic impacts on health care delivery models and practice. Meanwhile, in the more severely affected nations, large numbers of seriously ill patients have been hospitalised, many requiring very intensive levels of care, provided under stressful and demanding conditions.

The first year of the COVID-19 pandemic has inflicted deep financial challenges in many health care systems (whether or not they have experienced a large COVID-19 caseload), and a rising number of deferred healthcare services (Deloitte 2020); in badly affected nations and regions, the cost to health care systems has also included many deaths, severe illnesses and burnout amongst health professionals themselves. Yet these represent only the more immediate and short-term impacts of the pandemic on health systems.

Understanding is now emerging of a range of potential longer-term consequences, whose impacts may continue to be felt by health care systems for years to come. Some of the key factors which might be expected to have a long-term impact on health care systems and the approximate timing of their likely consequences are illustrated in Figure 1.

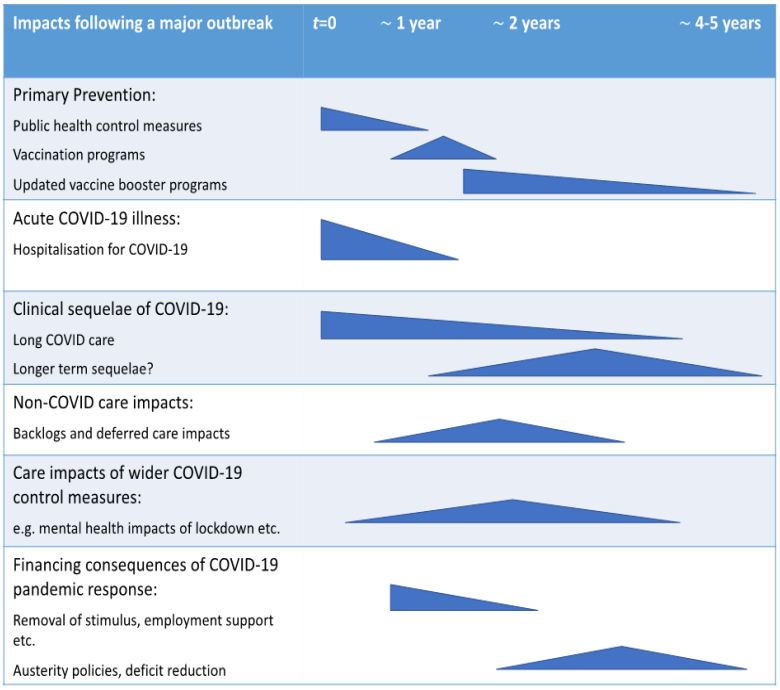


Figure 1. Possible health system impacts of COVID-19 over the short to longer term time horizon.

Even in Australia, where effective control measures have avoided the burden of acute and long-term illness from COVID-19 seen in so many other countries, many of these potential long-term impacts are still likely to be felt in the health care system. Significant resources will remain committed to public health control and case detection measures for months (if not years) to come. Australia's COVID-19 vaccination program has got off to a slow start and will clearly require the commitment of substantial health professional time for up to a year if it is to achieve its aim.

Australia also experienced the global phenomenon of large-scale reductions in health care utilisation and deferral of care (Moynihan et al. 2021). For instance, although there was an increase in urgent elective surgeries of about 3.5% between 2018-19 and 2019-20, there was a 9.2% decline in the overall volume of elective surgeries, indicating that a number of less urgent procedures had been cancelled or delayed due to COVID-19 restrictions (AIHW 2020). Another study in New South Wales reported a reduction of healthcare activities such as face-to-face consultations (22.1%), breast screening activity (51.5%), ambulance incidents (7.2%), emergency department visits (13.9%), public hospital inpatient episodes (14.3%) and public hospital planned surgical activity (32.6%) when March to June 2019 data are compared to the same months of 2020 (Sutherland et al. 2020). However, the large and rapid expansion of telehealth services (overwhelmingly via use of telephone consultations) meant that large numbers of patients were able to remain in contact with their providers, even as face-to-face activity dropped rapidly (Snoswell et al. 2021)

Missed care and backlogs have the potential to impact negatively on health outcomes. For example, based on the stage-shift model analysis, approximately 90 excess deaths and $12 million excess healthcare costs over a five-year period were predicted due to the 3-month delay in diagnosis and management of four cancers across Australia (Degeling et al. 2020).

Meanwhile, it is clear that COVID-19 and the social and economic impacts of control measures have had significant negative effects on mental health (Fisher et al. 2020), well-being and family violence (Burgess et al. 2021); whether these effects will persist in the longer-term is difficult to predict.

In terms of the health of healthcare workers in 2020, approximately half of the 2,707 healthcare providers from 60 countries reported burnout in a recently conducted cross-sectional survey (Morgantini et al. 2020). In Australia, approximately 30% of 320 healthcare workers surveyed screened positively for burnout symptoms (Dobson et al. 2021).

Responding to the pandemic has had significant financial impacts on the health care sector but has affected different segments in different ways. For example, despite overall growth in health care spending due to COVID-19, some small and private practices reported losses. According to the survey of 2,235 general practitioners (GP) and non-GPs working in private practices in Australia in mid-May 2020, a proportion of GPs (65%), non-GP specialist (83%), surgeons and anaesthetist (approximately 33%) reported a reduction in income (Scott 2020). In addition, those practising in urban or in affluent areas were most likely to note a decrease in income and suffer from financial stress and mental distress (Scott 2020).

However, overall MBS figures suggest that the total value of benefits paid to GPs and other professionals did not decrease during 2020 (AIHW 2021b). It was reported that practices adapted to the changes in workload via increasing revenue through altering work hours, using JobKeeper Payment subsidy, and increased bulk billing of telehealth consultations (Scott 2020). The total number of people with hospital private health insurance fell noticeably in the early months of COVID-19 (as did overall reported profits for the private health insurance industry) but had increased by the end of 2020 to levels not seen since early 2017 (APRA 2020, 2021).

Large increases in public expenditure by both the Commonwealth and state and territory governments have been central to Australia's overall success in responding to COVID-19; yet international experience suggests that misguided and premature withdrawal of stimulus spending and reversion to austerity measures is always a significant risk in the wake of major economic crises, often with very adverse consequences for the health sector (Hensher et al. 2020).

In many countries which have suffered more severely than Australia, concerns about the long-term consequences of the pandemic are increasingly focusing on the long-term clinical sequelae being seen in survivors of COVID-19, including Long COVID and a wide range of other conditions. In February 2021, WHO Europe (Rajan et al. 2021) released a policy brief on Long COVID, the conclusions of which provide a useful starting point for discussing the potential for a value-based approach to this challenge in Australia:

- "Although Long COVID is not yet fully understood, health policy-makers should be preparing to address it"
- "First step towards dealing with Long COVID should include implementing effective patient registers or other surveillance systems"
- "Care guidelines and multidisciplinary services need to be developed to ensure appropriate assessment and management of the condition"
- "Effective response can only be achieved by involving Long COVID patients themselves" (Rajan et al. 2021)

1.2 Value Based Health Care in the Time of COVID-19

An important movement in Australian and global health care in recent years has been the pursuit of "value based health care" (VBHC). Pioneered by Porter and Teisberg in the United States (Porter 2010; Porter & Teisberg 2006), VBHC seeks to ensure that the overarching goal of healthcare delivery should become the achievement of high value for patients. "Value" in healthcare is defined as the health outcomes that are important to the patient, relative to the cost of delivering those outcomes (Porter & Lee 2013) -or health outcomes achieved per dollar spent (Porter 2010). Porter's definition of value-based healthcare (VBHC) is based on value, with an overarching goal of improving patients' health outcome/s without increasing costs or reducing costs without sacrificing outcomes, or both (Porter & Lee 2013).

In countries with universal health care, meanwhile, competing approaches to "value in health care" have emerged which seek to extend Porter and Teisberg's concepts beyond their original focus on

patient-provider relationships in a competitive health care market, to make them more applicable to publicly-funded or social health insurance systems (Verhoeven et al. 2020). Indeed the World Health Organization has recently noted that achieving universal health coverage in low and middle-income countries will itself require a shift from the traditional focus on "value for money" to a broader focus on "value-based health services" (WHO 2021b).

Table 1 compares the original Porter and Teisberg definition of value with two expanded approaches – "Triple Value Health care" (Gray & Jani 2016), itself an extension and recasting of the "Triple Aim" concept (Berwick, Nolan & Whittington 2008), and the European "four pillars" approach to value in VBHC (Bodenheimer & Sinsky 2014; EXPH 2019).

Table 1. Concepts of "value" in VHBC.

Value Based Health Care Porter and Teisberg (2006)	**Triple Value Health care** Gray and Jani (2016)	**Four Pillars of Value in VBHC** EXPH (2019)
• Health outcomes (from the patient perspective) achieved per dollars spent • Outcomes are described as having 3 dimensions: ○ **capability:** ability of patients to do the things that define them as individuals and enable them to be themselves, ○ **comfort:** relief from physical and emotional suffering and ○ **calm:** ability to live normally while getting care (Teisberg, Wallace & O'Hara 2020).	• **Personal value:** "ensuring that each individual patient's values are used as a basis for decision-making in a way that will optimize the value for him or her" • **Technical value**: "ensuring that resources are *used* optimally". That is, achieving technical efficiency • **Allocative value:** "ensuring that resources are *allocated* optimally and equitably" for *populations.* That is, achieving allocative efficiency	• **Personal value:** "appropriate care to achieve patients' personal goals" • **Technical value:** "achievement of best possible outcomes with available resources" • **Allocative value:** "equitable resource distribution across all patient groups" • **Societal value:** "contribution of healthcare to social participation and connectedness"

Australian state and territory health departments and health system stakeholders have all expressed interest in and active support for the development of VBHC approaches and strategies to guide the development of the Australian health care system (Council on Federal Financial Relations 2020b; Woolcock 2019). Several are well advanced with the implementation of VBHC principles in priority programs (NSW Health 2020; Went West n.d.). The *Healthy People, Healthy Systems Blueprint*, published in January 2021, outlines a number of steps which would support implementation of VBHC concepts articulated in the 2020-25 Addendum to the National Health Reform Agreement (AHHA 2021). It suggests the following are needed to embed VBHC in Australia:

- A nationally unified and regionally controlled health system that puts patients at the centre.
- Performance information and reporting that is fit for purpose.
- An integrated workforce that exists to serve and meet population health needs, working via team-based models of care.
- Funding that is sustainable and appropriate to support a high-quality health system.

In the short term, the urgency of responding to the COVID-19 pandemic has moved the attention of policy makers away from system reform, due to the pressing need to respond operationally. It is clearly the case that VBHC, "value" and the economic evaluation of health care (for example, cost-effectiveness analysis, health technology assessment etc.) have effectively taken a back seat during much of the direct response to the COVID-19 pandemic. Core decisions on vaccines, treatments and care models understandably proceeded apace, largely on the basis of what was physically possible, rather than what might represent best value care. The availability of resources and the urgency of immediate needs have dominated, in a situation in which – temporarily at least – fiscal budget constraints have proved much less binding than many had previously assumed. This situation will not persist indefinitely, and the need to secure greater value in the allocation and use of health care resources will be as great as ever during the recovery from COVID-19 (AHHA 2020).

2 The Long-Term Clinical Sequelae of COVID-19

2.1 Evolving terminology and definition

There is no standardised collective diagnosis or nomenclature for the wide range of post-COVID-19 symptoms which have been observed in many countries (Callard & Perego 2021; Greenhalgh et al. 2020; Maxwell 2020). However, "Long COVID", also referred to as "ongoing post-acute-COVID-19 illness", "long tail of COVID", "post-acute covid-19", and "chronic post-COVID syndrome", has become the colloquial term for the extended and more complex course of COVID-19 (Callard & Perego 2021). Long COVID appears to be a multisystem disease characterised by a range of symptoms which fluctuate over time (Maxwell 2020). Patients living with long COVID have been referred to as "long haulers" (Callard & Perego 2021).

The UK National Institute for Health and Care Excellence (NICE) presented three terms describing the effects of COVID-19 depending on the duration of patient recovery from post-acute COVID-19 symptoms (NICE 2020). These include:

- **Acute COVID-19 infection:** which refers to the signs and symptoms of lasting for up to four weeks.
- **Ongoing symptomatic COVID-19:** which refers to symptoms lasting from 4 weeks up to 12 weeks.
- **Post-COVID-19 syndrome:** which refers to the signs and symptoms extended for more than 12 weeks after the initial presentation of acute symptoms.

The NICE panel argued that time-bound terminologies would better facilitate patient access to care, serve as grounds for service planning, and promote the establishment of clinical datasets for research and monitoring (Shah et al. 2021).

However, there were interesting debates related to the adaptation of these terminologies. Gorna et al commented that "post-COVID-19 syndrome" is based on assumptions, not fully consistent with what is known about the natural history of Long COVID, and seems to imply some degree of symptom abatement (Gorna et al. 2021). Alwan added that "Long COVID" is still the most appropriate term as it does not connote or assume a specific disease definition, rather it refers to the prolonged nature of the demonstrated symptoms (Alwan 2021). Meanwhile, NICE argued that the term "post COVID-19 syndrome" does not indicate patient recovery from the disease, rather it suggests only that the "acute phase" of COVID-19 had ended (Maxwell, Poole & Oustric 2021)

The patterns and symptoms of Long COVID have been used to further classify Long COVID patients. For instance, the honorary advisor of the ME Association in the UK divided patients with Long COVID into three groups:

- Post-COVID intensive care/hospital care syndrome consisting of patients who required hospitalisation due to severity of condition and are most likely needing further rehabilitation;
- Post/Long-COVID Self-Managed Syndrome consisting of patients who were mostly self-managed at home and still experiencing persisting symptoms such as shortness of breath, palpitation, high temperature, loss of taste or smell; and
- Post/Long-COVID Fatigue Syndrome and Post-COVID ME/CFS consisting of patients with symptoms akin to Post Viral Fatigue developing into myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) (Shepherd 2020).

It was noted that some of the Long COVID symptoms have similarities to PVS, PVFS and ME/CFS (see case definitions); however there are varying levels of severity and presentation of symptoms (Shepherd 2020). Various different syndromes have been suggested in addition to Long COVID, such as post-intensive care syndrome, PVFS, long term COVID syndrome and combinations of these syndromes at the same time (Maxwell 2020).

Three Long COVID categories derived from the literature have also been suggested including: "(1) residual symptoms that persist after recovery from acute infection; (2) organ dysfunction that persists after initial recovery; and (3) new symptoms or syndromes that develop after initial asymptomatic or mild infection" (Amenta et al. 2020). Another proposed classification adopted by the University of Cincinnati Medical Center categorises patients into five types (Type 1 to Type 5) according to the severity of the initial symptom, duration of the symptoms, period of quiescence and delayed onset of symptoms (Becker 2021).

Box 1. Case definition

Post Viral Fatigue (PVF) comes after the occurrence of any type of viral infection, often resolved in a few weeks (The ME Association 2020).

Post Viral Fatigue Syndrome (PVFS) is a prolonged period of ill health post-acute infection which often lasts for month and is accompanied by additional symptoms other than fatigue, but where a diagnosis of ME/CFS is not yet applicable (The ME Association 2020).

Myalgic Encephalomyelitis or Chronic fatigue syndrome (ME/CFS) is a debilitating illness with symptoms occurring for more than two to three months (The ME Association 2020). It is clinically defined by "dysregulation of the central nervous, cardiovascular and immune systems, endocrine dysfunction, and impaired cellular energy metabolism and ion transport"(Eaton-Fitch et al. 2020). Symptoms included post-exertional malaise, cognitive dysfunction, pain, sleep disturbance, ongoing flu-like malaise, and autonomic symptoms (The ME Association 2020).

Post-intensive care syndrome is the collective term whereby intensive care unit (ICU) survivors are more at risk of developing impairments in cognitive, mental and physical health (Brigham et al. 2021).

WHO Europe has recognized that knowledge relating to Long COVID is still evolving, noting that COVID-19 can cause persistent ill-health and is associated with a range of overlapping symptoms (Rajan et al. 2021). In September 2020, WHO also activated additional International Classification of Disease (ICD) codes to provide clarity between the acute phase and late effects of COVID-19 (WHO 2020c).

These classifications and terminologies will undoubtedly continue to evolve as new findings emerge. However, a standardised classification for use within national health systems is important to facilitate timely and appropriate provision of healthcare services. Australia's relatively small number of COVID-19 and Long COVID cases means that lessons from countries with greater experience of Long COVID and other post-COVID symptoms and syndromes should inform the development of definitions in Australia. Nevertheless, learning from international experience should not lead to delays in developing definitions and measures for domestic use.

2.2 Prevalence of Long COVID

Different study designs and samples to estimate the prevalence of Long COVID and other long-term sequelae of COVID-19 are evident in a growing international literature. Some larger population or survey-based studies report that approximately 13%-22% of patients infected with COVID-19 remain unwell after three or five weeks (ONS 2021b; Sudre et al. 2021), and 2-10% had persistent symptoms many months after diagnosis (ONS 2021b; Sudre et al. 2021). Clinical cohort studies reported estimates varying from 32% to 87% due to different sample size, methodology and follow-up period (Arnold et al. 2021; Carfì, Bernabei & Landi 2020; Nehme et al. 2020).

The interim result of the ongoing Australian prospective study (the ADAPT study) showed that approximately 40% (n=31/78) of the enrolled participants had ongoing fatigue (n=17), shortness of breath (n=15), and chest tightness (n=4) after 9.8 weeks of diagnosis (Darley et al. 2021b).

Of this cohort, seven were hospitalised and 24 were managed in the community setting. The study also reported that 35% of the patients managed in the community had extended symptoms several months after COVID-19 infection (Darley et al. 2021b). A preprint follow-up of this report indicated that 32% had persistent symptoms and 19% had Long COVID 8 months post initial infection (Darley et al. 2021a).

A telephone interview study undertaken in the United States found that 35% (n=95) of the 292 respondents who tested positive in reverse transcription-polymerase chain reaction (RT-PCR) test for SARS-CoV-2 had not yet returned to their full health state two to three weeks after testing. Of this cohort, 26% were young adults ages 18-34 years old (Tenforde et al. 2020). In an Italian study, 87% of hospitalised COVID-19 survivors (n=143) reported ongoing symptoms 8.6 weeks after the initial presentation of acute COVID-19 infection (Carfì, Bernabei & Landi 2020). A longer cohort study in Wuhan, China reported that 76% (n=1,265/1,655) of COVID-19 survivors reported experiencing at least one symptom six months after discharge (Huang et al. 2021).

The full long-term consequences of COVID-19 are still uncertain (Rajan et al. 2021), and only a few studies have thus far investigated the risk factors which may predict Long COVID illness. International studies report that persistent symptoms and worsened complications are common in patients who had been hospitalised with COVID-19 with prevalence ranging from 51% to 87% (see Appendix 1, Figure 7 for the prevalence estimates in hospitalised patients) (Arnold et al. 2021; Carfì, Bernabei & Landi 2020; Huang et al. 2021; Jacobson et al. 2021; Morin et al. 2021; Sykes et al. 2021; Tomasoni et al. 2021). Other international studies reported that many non-hospitalised survivors also experience persistent and severe complications from COVID-19 (see Appendix 1 Figure 8 for the prevalence estimate in non-hospitalised patients) (Stavem et al. 2021; Sudre et al. 2021).

In terms of gender, some international studies reported that Long COVID is more commonly observed in women (Sudre et al. 2021; Venturelli et al. 2021). Based on recent data released by the UK's Office for National Statistics (ONS), a higher female prevalence of Long COVID was observed in the UK (24% female and 21% male) (ONS 2021b). Similarly, in the cohort study undertaken in Wuhan, China, a higher percentage of Long COVID illness was found in women (81%) compared to men (73%) (Huang et al. 2021).

Post-acute COVID-19 symptoms were not only observed in adults but also in younger age groups. The ONS found that prevalence of Long COVID in the 2-11, 12-16 and 17-24 age groups was 13%, 15% and 17% respectively (ONS 2021c). The highest prevalence of Long COVID was between the ages of 25-69 (25-27%). Meanwhile, the prevalence of Long COVID in people aged over 70 was 18% (ONS 2021c). It has also been reported in the UK study that patients with a greater number of symptoms experienced during the acute phase and a pre-existing condition were more likely to experience prolonged COVID-19 illness (Sudre et al. 2021). Those who experienced five or more symptoms during the first week of illness were more likely to experience Long COVID, with an odds

ratio (OR) of 3.53. A pre-existing condition of asthma increased the likelihood of a patient experiencing Long COVID with an odds ratio of 2.14 (95% CI: 1.55 to 2.96).

More evidence is still needed to confirm confidently the relationship between factors such as the severity of acute COVID-19, gender, pre-existing conditions and age, and the likelihood of a patient developing Long COVID.

2.3 Symptoms and complications of COVID-19 after the acute phase and its effects on patients' quality of life

The reported symptoms of Long COVID and other complications of COVID-19 regardless of patient hospitalisation status are shown in Table 2. These presentations have been grouped according to the WHO's International Classification of Disease, version 11 (ICD-11), which provides a standard for systematic recording, reporting, analysis, interpretation and comparison of mortality and morbidity data (WHO n.d.). Patients living with Long COVID and many COVID survivors had varying presentations of newly developed or worsened symptoms and conditions affecting multiple parts and organs of the body (Table 2).

Table 2. COVID-19 sequelae presentation grouped according to ICD-11 Chapter.

Sequalae of COVID-19 grouped according to ICD-11		
Classification	**Reported diagnosis or symptom**	**Reference**
Diseases of the Immune System	• mast cell activation syndrome • new-onset allergies and anaphylaxis	(Gorna et al. 2021)
Diseases of the Circulatory System	• myocarditis or pericarditis • microvascular angina • thromboembolic disease (pulmonary emboli) • heart failure • arrhythmias • systolic dysfunction	(Dennis et al. 2021; Donnelly et al. 2021; Gorna et al. 2021; Maxwell 2020; Willi et al. 2021a)
Diseases of the Respiratory System	• interstitial lung disease* • impairment in lung • pulmonary fibrosis	(Ayoubkhani et al. 2021a; Dennis et al. 2021; Gorna et al. 2021; Willi et al. 2021a)
Diseases of the Nervous System	• dysautonomia including postural orthostatic tachycardia syndrome • thromboembolic disease (cerebral venous thrombosis) • myelopathy • neuropathy	(Gorna et al. 2021)

Sleep-wake disorders	• sleep difficulties • poor sleep quality	(Huang et al. 2021; Mandal et al. 2020)
Mental Health, behavioural or neurodevelopmental disorder	• depression • PTSD • neurocognitive disorders • anxiety	(Gorna et al. 2021; Halpin et al. 2021; Huang et al. 2021; Mandal et al. 2020; Mazza et al. 2020; Taquet et al. 2021)
Endocrine, nutritional or metabolic diseases	• diabetes • thyroiditis	(Ayoubkhani et al. 2021b; Dennis et al. 2020; Gorna et al. 2021; Huang et al. 2021)
Diseases of the liver and pancreas are under the high level code of Digestive system	• organ impairment (pancreas) • hepatitis • liver problem or impairment	(Dennis et al. 2021; Gorna et al. 2021; Maxwell 2020)
Diseases of the Genitourinary system	• renal impairment	(Dennis et al. 2021; Gorna et al. 2021; Maxwell 2020)
Diseases of the Musculoskeletal system and connective tissue	• muscle pain • muscle weakness	(Dennis et al. 2021; Huang et al. 2021)
Diseases of the Skin	• hair loss	(Huang et al. 2021)
Symptoms, signs or clinical findings, not elsewhere classified	• fatigue • joint pain • breathlessness or shortness of breath • headache • brain fog • chest pain • abnormal liver enzymes • cough • dysphonia • skin rashes which could take forms like vesicular, maculopapular, urticarial, or covid toe-chilblain-like lesions on the extremities	(Carfì, Bernabei & Landi 2020; Darley et al. 2021b; Dennis et al. 2021; Gorna et al. 2021; Greenhalgh et al. 2020; Halpin et al. 2021; Huang et al. 2021; Ladds et al. 2020; Mandal et al. 2020; Sudre et al. 2021; Tenforde et al. 2020;

	• splenomegaly • symptoms related to communication, voice, swallow and laryngeal sensitivity • abnormal chest imaging manifestations • smell disorder • palpitations • anosmia	Townsend et al. 2020; Wong et al. 2020)
Codes for special purposes	• Paediatric Inflammatory Multisystem Syndrome, Temporally associated with SARS-CoV- 2 (PIMS-TS)	(Bannock 2021; Broad et al. 2021)

*rare

Fatigue and dyspnoea are the two most frequently reported symptoms experienced by long-haulers (Halpin et al. 2021; Mandal et al. 2020; Sudre et al. 2021; Tenforde et al. 2020; Townsend et al. 2020). In the study held in Dublin Ireland, 52.3% (n=67/128) of patients who tested positive with COVID-19 reported ongoing and severe fatigue 10 weeks after the initial presentation of COVID-19 symptoms (Townsend et al. 2020). It was noted that fatigue had so severely affected the survivors such that one-third of the participants had not yet returned to their previous employment (Townsend et al. 2020).

Approximately half of the COVID-19 survivors from different international cohort studies reported a worsened quality of life after contracting the disease (Halpin et al. 2021; Maxwell 2020; Wong et al. 2020). In the Italian study of the 143 patients who recovered from COVID-19 [1], 44.1% had worsened quality of life measured using the EQ-5D questionnaire [2] (Carfì, Bernabei & Landi 2020). Another study in the UK reported that 52% of the observed low-risk individuals had difficulty in undertaking usual activities (Dennis et al. 2021). In qualitative research in the UK with 114 participants, COVID-19 survivors reported that they had a significant decline in their ability to perform basic activities (Ladds et al. 2020). Another UK study reported that 68.8% of patients who were managed in an intensive care unit (ICU) (n=32), and 45.6% of patients managed in the ward (n=68) had a clinically significant decline (at least 0.05) in EQ-5D-5L total scores (Halpin et al. 2021).

2.4 Other serious symptoms and complications of COVID-19 after the acute phase

A range of diagnoses which might reasonably give cause for concern regarding their potential to signal future illness and disability is also evident (Table 2). Serious complications or organ impairment, mental health conditions, possibility of readmission and mortality from the acute phase, and long-term conditions seen in children have been widely reported in the literature (Table 2).

[1] *as defined by the WHO recovery-no fever for 3 consecutive days, improvement in other symptoms, and 2 negative test results for severe acute respiratory syndrome coronavirus 2 [SARS-CoV-2] 24 hours apart*
[2] *is a multi-attribute utility (MAU) tool to measure health-related quality of life in cost-effectiveness analysis (EuroQol n.d.)*

Serious complications have also been reported in different studies of patients who have experienced COVID-19 illness. For instance, in the UK study, a quarter of 201 low-risk individuals with Long COVID syndrome experienced mild systolic dysfunction or myocarditis three months after COVID-19 infection (Dennis et al. 2021). The NICE rapid review noted that 8 to 12% of discharged COVID-19 patients were diagnosed with heart failure and arrhythmias (Maxwell 2020).

In the ongoing prospective longitudinal study in the UK including 201 low-risk participants with persistent COVID-19 symptoms, approximately 70% (mostly without risk factors and pre-existing condition or hospitalisation) had an impairment in one or more organs four months following initial symptoms of COVID-19 infection (Dennis et al. 2021). Organ impairment was observed more in patients who were hospitalised compared to non-hospitalised (Dennis et al. 2021). In the retrospective cohort study in the UK, which included 47,780 patients in its analysis, findings showed that post-discharge multi-organ dysfunction such as respiratory disease, diabetes and cardiovascular events were significantly elevated in patients admitted with COVID-19. They also noted that the elevated risk is not confined to the older population and was similar across ethnicities (Ayoubkhani et al. 2021a). A systematic review, aiming to synthesize the existing evidence around intermediate and long-term COVID-19 sequelae of previously healthy individuals infected with COVID-19, concluded that COVID-19 affected different organ systems. It was agreed that lung damage in the form of residual pulmonary fibrosis and cardiac damage could be significant long-term sequelae of COVID-19 (Willi et al. 2021b).

Significant mental health consequences have also been observed in COVID-19 survivors and in patients with Long COVID. An unstructured clinical interview of 402 COVID-19 survivors in Italy reported that a higher incidence of post-traumatic stress disorder (PTSD), depression and anxiety are expected in COVID-19 survivors (Mazza et al. 2020). A large study of adult COVID-19 survivors, mainly using US electronic health record data, published in April 2021 showed a clearly increased risk of being newly diagnosed with a psychiatric disorder after suffering COVID-19 (including mood, anxiety and psychotic disorders and substance abuse (Taquet et al. 2021). Increased incidence and relative risk of psychiatric disorders were higher in those who had been hospitalised for COVID-19, but still clearly visible in non-hospitalised patients. The same study also showed that COVID-19 survivors display an increased incidence of several neurological conditions, including intracranial hemorrhage, ischaemic stroke, Parkinsonism, nerve/root or plexus disorders, myoneural junction of muscle disease, encephalitis and dementia (Taquet et al. 2021).

A few studies have emerged presenting information on readmission and mortality after the acute COVID phase. In the US, it has been reported that 20% of COVID-19 survivors were readmitted with diagnoses of sepsis, pneumonia or heart failure, and 10% died within 60 days of their original hospital discharge (Donnelly et al. 2021). The 60 day follow-up readmission and mortality rates were lower when compared to matched patients with heart failure and pneumonia. However, rates were higher 10 days post-discharge indicating that there is an increased risk of clinical deterioration during this period (Donnelly et al. 2021). A retrospective cohort study in England reported that out of 47,780 discharged COVID-9 survivors, 29.4% and 12.3% were readmitted and died respectively over the study period. The study noted that COVID-19 patients who were discharged from the

hospital were 3.5 and 7.7 times more likely to be readmitted or to die respectively, when compared with the matched controls (similar demographic and clinical profiles) (Ayoubkhani et al. 2021a).

In contrast to these two studies, lower readmission (n=25/2,469) and mortality (n=33/2,469) rates due to exacerbation of disease six months after hospital discharge were observed in Wuhan, China (Huang et al. 2021).

In children, paediatric inflammatory multi-system syndrome (PIMS) also known as Paediatric Inflammatory Multisystem Syndrome, Temporally associated with SARS-CoV- 2 (PIMS-TS) or Multisystem Inflammatory Syndrome in Children (MIS-C) was estimated to affect 0.02% (one in 5,000) of children who had COVID-19 irrespective of the absence and presence of symptoms and was reported to have caused the death of two children in the UK (Bannock 2021; Broad et al. 2021). PIMS was hypothesized to have links with COVID-19 and is characterised by rashes, elevated temperature, low blood pressure, tachycardia and abdominal problems. This condition is comparable but distinct to Kawasaki disease (Broad et al. 2021; ECDC 2020; Lewin 2020), and is more common in male or obese patients and ethnicities other than Anglo-European (Ahmed et al. 2020b; Bannock 2021; Broad et al. 2021; Lewin 2020).

In a retrospective study undertaken including 70 children diagnosed with PIMS in South East England, black, Asian and other ethnic groups or from deprived IMD quintiles are more likely to have PIMS-TS with an odds ratio of 15.7, 4.0, and 5.2 respectively (Broad et al. 2021). Limitations of their study, such as small sample size, rarity of the disease, and consistency of the disease definition were acknowledged. In a systematic review of MIS-C, higher rates of PIMS-TS were found in the African American or Afro-Caribbean groups (Ahmed et al. 2020b). There have been a few documented PIMS cases in Australia, as reported by the Royal Australian College of General Practitioners (RACGP) in September 2020 (Lewin 2020).

Symptoms of Long COVID similar to those found in adults have also been seen in paediatric cases. For example, a cross-sectional study in Italy (preprint), found that more than half of the 129 children reported at least one lingering symptoms 17 weeks since COVID-19 infection. Symptoms reported included fatigue, respiratory problems, muscle and joint pain, headache, insomnia, and palpitations (Buonsenso et al. 2021).

While these studies have given insights into what symptoms might occur after the acute phase (Table 2), there is still an evidence gap relating to why and how these symptoms occur. For instance, a study in the UK suggested that PTSD incidence in post-ICU COVID-19 survivors was in line with that experienced by patients with other conditions following ICU discharge (Halpin et al. 2021). Others noted that “psychiatric consequences” might be caused by an immune response to COVID-19 or psychological stressors (Mazza et al. 2020).

It has also been postulated that morbidity could be related to persistent virus infection (Jacobs 2021). In addition, it has been speculated that the higher incidence of enduring neurological symptoms they observed (and their stronger correlation with original severity of COVID-19 illness) might reflect a more direct physiological mechanism at work, while the weaker relationship between

psychiatric disorders and original disease severity might reflect "…at least partly, the psychological and other implications of a COVID-19 diagnosis rather than being a direct manifestation of the illness" (Taquet et al. 2021).

Studies have not yet been able to provide a definite conclusion on the underlying physiological mechanisms of long-term post-COVID illness, including Long COVID.

2.5 Other potential long-term consequences – lessons from history

The long-term consequences of COVID-19 are – by definition - still unknown, and emerging studies relating to Long COVID and other post-COVID symptoms and syndromes can only provide information on the short or medium consequences observed in the year since the COVID-19 pandemic began. Parallels have been drawn between the likely long term consequences of COVID-19 based on the symptoms observed during its acute phase (Arnold 2020) and those that followed previous pandemics such as Russian influenza (Honigsbaum & Krishnan 2020), Parkinsonian syndromes after the 1918 influenza pandemic (Taquet et al. 2021), Ebola and Chikungunya virus (Geddes 2021), Severe Acute Respiratory Syndrome (SARS) and Middle East Respiratory Syndrome (MERS) (Ahmed et al. 2020a).

Box 2. Lessons from history

The Russian influenza epidemic of 1889 was an influenza mass outbreak initially seen at St. Petersburg, which spread rapidly across Europe and the rest of the world causing an estimated one million deaths (Honigsbaum 2020). Lingering symptoms were documented, such as weakness, fatigue, insomnia and little improvement months after acquiring Russian Influenza (Honigsbaum & Krishnan 2020). This pandemic was also noted as the cause of the stunted growth of about 2.7 cm in men who were *in utero* between 1889 and 1893 in Scotland, indicating that the disease could be transmitted in the womb (Green 2020; Riggs & Cuff 2013).

The 1918-19 pandemic or the Spanish Flu was caused by H1N1 virus that infected one-fifth of the world's population and killed between 20 to 100 million people (Cummings 2018). Spanish flu has been dubbed as the deadliest pandemic recorded in modern history, and conditions were aggravated due to global war and inadequate leadership. Spanish flu infected young adults and spread in almost every part of the world (Cummings 2018).

Following the acute phase of Spanish Flu, neurological conditions appeared in some survivors, including delirium, cycloplegia, encephalitis lethargica - manifested by elevated temperature, ophthalmoplegia, mental confusion, and lethargy. It was reported that approximately 80% of the patients who recovered from encephalitis lethargica later developed a post-encephalitic Parkinson's disease (Henry et al. 2010).

Those who were born or were young during the period of the Russian and Spanish flu pandemics were found to have a two-to-three-fold increase in their risk of developing Parkinson's disease compared to those born outside that period (Henry et al. 2010). In terms of hospitalisation in the long term, individuals exposed to Spanish flu while *in utero* were found to have a higher number of hospital visits compared to the unexposed.

Results also showed that those with in utero exposure to the second, more deadly wave (September to December 1918) of the pandemic experienced higher rates of functional limitations when compared to those exposed to the milder first and third waves or those with no exposure to the 1918-19 pandemic (Acquah, Dahal & Sloan 2017).

The 2014 to 2016 Ebola virus outbreak was the largest Ebola outbreak since the initial appearance of the virus in 1976 in Nzara, South Sudan and Yambuku, Democratic Republic of the Congo. The 2014 outbreak began in Guinea and then moved to Sierra Leone and Liberia (WHO 2020b). The Ebola Virus disease (EVD) is a serious and fatal illness with an average case fatality rate of approximately 50% (WHO 2020b). For survivors, recovery from EVD is associated with long-term consequences such as rheumatologic, ocular, neurological disorders, depression, insomnia, fatigue, anxiety and post-traumatic stress all having been documented and acknowledge in the literature (Lötsch et al. 2017).

Chikungunya virus (CHIKV) is a virus transmitted to humans by *Aedes albopictus* and *Aedes aegypti* mosquitoes infecting an estimated 1.6M people(van Aalst et al. 2017). The virus, firstly seen in 1952 in Tanzania, occurred in tropical and subtropical sites worldwide mostly in Africa, Asia and the Indian subcontinent. An outbreak in America was recorded in 2015 and sporadic outbreaks are noted elsewhere (WHO 2020a). The symptoms of CHIKV included severe arthralgia, high fever, myalgia and headache. Long-term consequences included persistent arthralgia, arthritis, alopecia and depression, and these were more common in females and older age groups (van Aalst et al. 2017).

Coronavirus is a large family of RNA viruses causing **SARS and MERS** outbreaks (Zhu et al. 2020), and includes SARS-CoV-2, the virus causing COVID-19. The pathogen that caused SARS is SARS-CoV-1 (RNA virus) which infected approximately 8,000 people (Zhu et al. 2020). SARS emerged in Foshan China in November 2002 and subsequently spread to Hong Kong and worldwide (Zhu et al. 2020). The virus was contained in July 2003 in Taiwan, and there were only four small outbreaks thereafter (Zhu et al. 2020). After May 2004, there were no reported cases until a decade later, when a case was reported (Zhu et al. 2020). SARS symptoms included cough, fever, dyspnea and diarrhoea (Zhu et al. 2020). The case fatality rate of SARS is 9.6% (Zhu et al. 2020).

MERS is caused by the MERS-CoV strain, and an outbreak was first seen 2012 in Jordan with epidemic and sporadic cases since then (Zhu et al. 2020). A recent case was reported in Riyadh in March 2020 (Zhu et al. 2020). The total number of cases is about 2,500 with a case fatality rate of 34.3% (Zhu et al. 2020). MERS symptoms included fever, cough and shortness of breath (Zhu et al. 2020).

To date, there are neither treatments or vaccines for SARS and MERS (Zhu et al. 2020). Long term effects observed in SARS and MERS survivors include lung function abnormalities, psychological impairment such as depression, PTSD, and anxiety, and reduced exercise capacity post infection (Ahmed et al. 2020a). A significant reduction in health-related quality of life was also observed one-year post discharge (Ahmed et al. 2020a).

Neurological manifestations were also observed in SARS and MERS survivors, such as epilepsy, myopathy, stroke, chronic post-SARS syndrome characterised by persistent fatigue, diffuse myalgia, weakness, depression, nonrestorative sleep, confusion, seizure, sudden onset of diabetes, polyneuropathy etc (Verstrepen, Baisier & De Cauwer 2020). Approximately 10% of SARS survivors were observed to have a ME/CFS like illness (Shepherd 2020).

The described historical experience (Box 2) suggests that the emergence of long-term complications and sequelae following the COVID-19 pandemic would be unsurprising and entirely consistent with the experience of past pandemics and major viral disease outbreaks. In particular, a variety of potential neurological sequelae have been discussed. Concerns have been expressed that COVID-19 survivors might be at higher risk of developing dementia, as earlier research has found links between patients who had an episode of delirium and later had dementia (Arnold 2020). A meta-analysis concluded that patients who had delirium during hospital admission had double the risk of developing long-term cognitive decline (Goldberg et al. 2020), although the association between the two is still unclear and longer follow up studies are needed. Given the large proportion of patients hospitalised for COVID-19 who have experienced delirium, it was noted that there might be a spike of dementia cases in the long term (Arnold 2020). A retrospective cohort study in the US later found that COVID-19 survivors have an increased rate of dementia (Taquet et al. 2021).

COVID-19 prolonged symptoms may resemble those of the Russian Influenza sequelae, including neuralgia, neurasthenia, neuritis, nerve exhaustion, grippe catalepsy, post-grippal numbness, psychoses, prostration, inertia, anxiety, and paranoia (Honigsbaum & Krishnan 2020). One notable condition associated with Spanish Flu was Parkinson's disease, which has also been speculated to have links with COVID-19 (Sulzer et al. 2020). In a large retrospective cohort study and time-to-event analysis using mainly US data, evidence of increased incidence of Parkinsonian syndromes was found in COVID-19 survivors (Taquet et al. 2021). Limitations of the study included low incidence and some non-significant hazard ratio results but speculate that Parkinsonism might "…be a delayed outcome, in which case a clearer signal might emerge with a longer follow-up."

Despite the differences between COVID-19 and Ebola and Chikungunya, scientists pointed out that these viruses result in similar long term impacts, whereby survivors show lingering symptoms after the acute phase potentially causing lasting health problems (Geddes 2021). Approximately 80% of Ebola survivors had prolonged symptoms such as fatigue, fever, musculoskeletal pain, headache, depression, abdominal pain and ocular disorders one year after discharge (Scott & Semple 2017). In the case of Chikungunya, 20% of the infected patients are left with post-viral chronic inflammatory joint disease and some had fatigue (Scott & Semple 2017).

Post-SARS symptoms such as fatigue and depression have also been observed in patients with COVID-19 (Huang et al. 2021; Mandal et al. 2020). As COVID-19 is in the same coronavirus family and displays similar pathophysiology to SARS and MERS, the long-term effects found in these previous coronavirus infections have been directly compared with those observed in COVID-19 survivors (Greenhalgh et al. 2020; O'Sullivan 2021).

These historical data provided insights in terms of understanding the possible long-term outcomes of COVID-19. Also, these studies made recommendations on the importance of long-term follow up, investigating drugs or immunotherapies related to post-viral syndromes, and ensuring adequate diagnostic tests and rehabilitation pathways can prevent or at least manage any potential surge of patients who might progress to a more severe chronic illness (Ahmed et al. 2020a; Geddes 2021; Scott & Semple 2017).

Long COVID is already challenging a number of health care systems in badly affected nations; it is important not to ignore the potential for other, longer term conditions also to emerge as sequelae of COVID-19 illness in some patients, and for system managers and policymakers to be prepared accordingly.

2.7 Potential long-term burden of COVID-19 sequelae in Australia

To date, Australia is one of a group of countries who have succeeded in limiting and largely controlling the spread of COVID-19 within their borders. As a result of these effective control measures, Australia has suffered a much lower burden of COVID-19 disease than most other countries; rates of infections and deaths in Australia have been an order of magnitude lower than those seen in most other high-income nations (Appendix 2). If this low rate of infection can be maintained, the absolute long-term burden of COVID-19 in Australia will be correspondingly lower than in worse-affected nations. We have estimated likely current case numbers for Long COVID in Australia and explored some possible scenarios for their future evolution. The rapidly evolving international literature has been reviewed (as at late March 2021) in regard to the prevalence over time of Long COVID and associated syndromes in

- patients who had been hospitalised for COVID-19 and
- non-hospitalised COVID-19 cases.

Details of the methods and results of this review are provided (Appendix 1). It was found that these estimates are highly uncertain, involved a wide range of methods and populations, with complex limitations and potential biases involved in all the underlying studies reviewed. Broadly speaking, larger population-based studies have tended to generate lower estimates of Long COVID prevalence amongst COVID-19 survivors than have clinical cohort studies.

Long COVID symptoms are more common in patients who had been hospitalised for COVID-19; that prevalence estimates for in non-hospitalised patients vary widely; and that follow-up studies appear to show Long COVID prevalence decreasing over time.

The largest, most comprehensive and robust studies of the prevalence of Long COVID have been undertaken by the UK Office of National Statistics (ONS). In a study that followed up over 9,000 COVID survivors, the ONS found that 22.1% of patients in the UK showed Long COVID symptoms five weeks after diagnosis, falling to 9.8% 12 weeks after diagnosis (ONS 2021b). In April 2021, the ONS released new results from a larger study with over 20,000 participants who tested positive with COVID-19 between 26 April 2020 and 6 March 2021, showing that 13.7% of patients who tested positive for COVID continued to experience Long COVID symptoms after 12 weeks, and 12.2% at 18

weeks (ONS 2021a). In a population-based survey that formed part of this study, the ONS estimated that some 70,000 people across the UK still displayed symptoms of Long COVID fully twelve months after infection (ONS 2021a).

While very much smaller, a 2021 Australian study (Darley et al. 2021a) found 18.5% of their cohort of 99 patients still showed Long COVID symptoms at 34 weeks after testing positive with SARS-CoV-2 PCR. In order to generate simple and pragmatic estimates of Long COVID prevalence for application to Australia, we have used the initial ONS results of 9.8% prevalence at 12 weeks (ONS 2021b) as a conservative lower bound, and estimates of 18.5% at 34 weeks (Darley et al. 2021a) as a plausible upper bound. The total cumulative number of recorded COVID-19 cases across Australia used in this analysis was 29,260, as of 29th March 2021. Figure 2 shows the distribution of recorded COVID-19 cases across the country; Figure 3 shows the resulting range of estimates for Long COVID.

Figure 2. Total Cumulative Confirmed COVID-19 cases (to 29 March 2021).

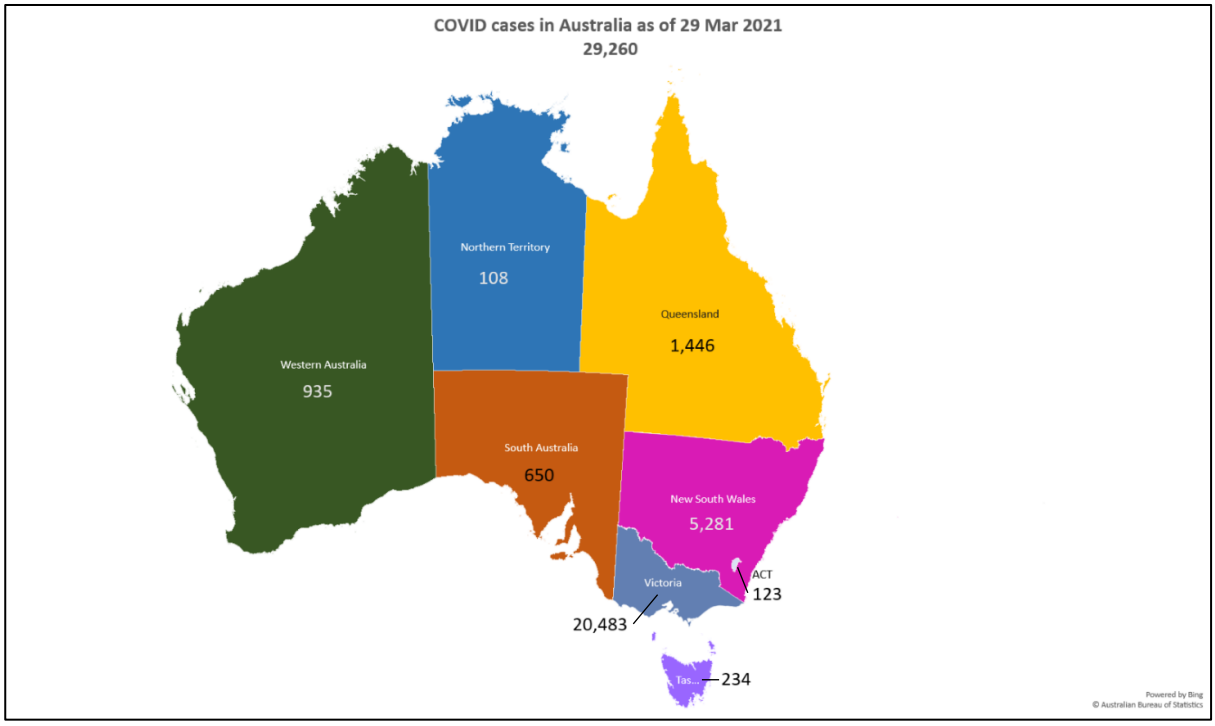
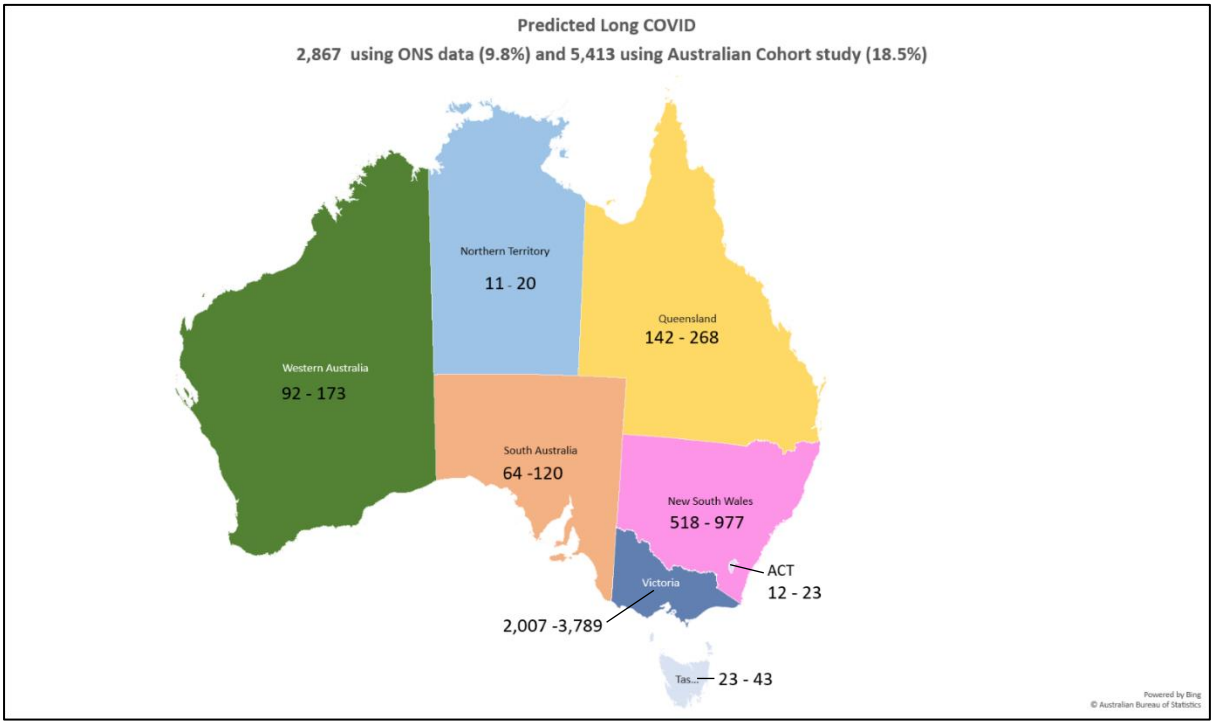


Figure 3. Estimated Long COVID cases as of 29 March 2021 (low – high estimates).



This analysis suggests that, nationwide, there might be between 2,867 and 5,413 Long COVID cases. Given the passage of time since the major outbreaks of 2020, it is highly likely that the number of current Long COVID cases has reduced further; however, these estimates are a useful starting point for discussing the potential magnitude of Long COVID in Australia.

Some 70% of these estimated cases would be found in Victoria, reflecting the larger caseload suffered in this state during its second wave in winter 2020. Another 18% of total cases are likely to reside in New South Wales (reflecting that state's higher burden in the first wave in early 2020), with only small numbers spread across the rest of the country. Evidence on the prevalence of longer-term organ damage and impairment likely to lead to future illness and disability (beyond Long COVID) remains unclear and limited (see Appendix 3), and despite showing reason for concern, is not yet robust enough to allow quantification of likely future burden.

A number of Australian COVID-19 survivors of intensive care will undoubtedly be suffering the effects of post-intensive care syndrome (PICS), but again, prevalence estimates are limited, and Australian case numbers fortunately have not been large to date (see Appendix 4). To date, some 19% of hospitalised cases have required ICU care for COVID-19 across Australia (around 780 ICU cases). Given existing understanding of PICS, we might expect that at least 50% of these COVID-19 ICU survivors might display the long-term physical, mental and cognitive impairments that characterise PICS, with profound long-term disability and impairment continuing in up to a third (see Appendix 4).

The future evolution of the number of patients with Long COVID, organ impairment and PICS in Australia depends entirely on the evolution of the COVID-19 pandemic itself, primarily whether Australia succeeds in avoiding any further major outbreaks. This, in turn, depends on a range of variables, including:

- the speed, take-up and efficacy of Australia's COVID vaccination program;
- maintaining effective quarantine measures to prevent importation of infections;
- continued social compliance with control measures; and
- whether problematic variants become a threat (for example, vaccine resistant variants); and
- the success or failure of control measures throughout the region and world as a whole.

None of these factors can be predicted reliably. Instead, three scenarios (plain sailing, speed bump, control failure) illustrate different possibilities.

Box 3: Predicted case number scenarios

Plain sailing – Australia's vaccination program is quickly redesigned following recent setbacks, achieving high levels of coverage by late 2021; meanwhile, border controls, quarantine, testing and contact tracing continue to be effective in preventing any large outbreaks from occurring. A trickle of new Long COVID cases continues to develop among international arrivals who had been infected prior to arriving in Australia; but some longer-standing Long COVID cases resolve with the passage of time. Overall, the total number of Long COVID cases falls over time.

Speed bump – Thrown off balance by supply problems and over-reliance on AstraZeneca, Australia's vaccination program proceeds only slowly, leaving a large proportion of the population unvaccinated for most of 2021. If a hotel quarantine break-out were to remain undetected long enough to become firmly established in the community in a major capital city, then an outbreak on the scale of that previously seen in Victoria could once again occur before effective control measures succeed in shutting down transmission. Six months after the peak of such an outbreak as many as five thousand patients could display symptoms of Long COVID.

Control failure – Under this third scenario, slow vaccination roll-out might combine with a hotel quarantine breach by a COVID-19 variant for which available vaccines offered only partial protection. The public is increasingly resistant to lockdown and control measures, yet is largely unprotected by vaccination, causing a substantial failure of a state government's public health controls. While the outbreak is contained in the rest of the country through grinding lockdowns and hard border closures, the state at the epicentre experiences infection rates similar to those seen in Germany, with over 250,000 infections occurring in that state alone. As the dust settles, it becomes clear that not only have more than 7,000 died, but between 24,000 and 46,000 patients need care for Long COVID in the months that follow, and more than 3,000 survivors continue to suffer the disabling long-term impacts of PICS.

It is worth remembering just how successful Australia has been to date in controlling COVID-19. Had Australia taken a different path and experienced infection numbers similar to those seen in Western European nations such as France, the UK and Sweden (6,000 to 7,000 cases per 100,000 population,

and cumulative death rates of 130 to 180 per 100,000 population – see Appendix 2), we could by now have been counting the cost of 33,000 to 46,000 deaths, between 150,000 to 240,000 Long COVID cases, and 20,000 or more PICS cases.

Considering these simple scenarios (and the counterfactual of what has actually happened in the rest of the world), it is therefore not especially contentious to suggest that the most important strategy for mitigating Long COVID and other long-term health impacts of COVID-19 will continue to be effective primary prevention – border control, quarantine, testing, contact tracing, mass vaccination, and effective control of local outbreaks when they occur.

Effective clinical and social support for COVID-19 survivors is essential – but the best way to minimise the long-term burden of COVID-19 on the Australian population remains preventing SARS-CoV-2 from gaining a foothold here.

3 Health system responses to the long-term consequences of COVID-19

3.1 Emerging clinical guidelines

In response to the growing number of patients with Long COVID, clinical guidelines have emerged to guide healthcare workers on how to better manage these patients (RACGP 2020; Shah et al. 2021; Taskforce 2021; WHO 2021a). Appendix 5 presents a summary of these living guidelines from a number of countries.

In Australia, the RACGP has published guidance on 'Caring for adult patients with post-COVID-19 conditions' (RACGP 2020). This guidance lays out a range of the COVID-19 sequelae discussed previously, and then describes the most common scenario likely to present to GPs, "nonspecific multisystem post-viral symptoms", with brief recommendations on management.

A Post-COVID-19 Conditions HealthPathway is also available online for clinicians as a resource on how to manage patients with post-COVID symptoms, as part of the Health Pathways suite used by many Primary Health Networks. The site includes information related to treatment approaches, assessment tools, investigations, rehabilitation referrals, community and financial support (Health Pathways 2021). This HealthPathway covers "post-acute COVID-19 - illness extending beyond 3 weeks from initial symptoms", and "chronic COVID-19 - symptoms extending beyond 12 weeks from initial symptoms." It provides guidance on assessment, management options within primary care, and a range of referral options for specialist assessment or rehabilitation.

In areas of Melbourne, the HealthPathway has also been customised to link with community health services, such as cohealth and its role in the North West Melbourne COVID Referral and Pathways Service. In March 2021, the National COVID-19 Clinical Evidence Taskforce also produced a flowchart to guide Care of people who experience symptoms post-acute COVID-*19*, linking in part to the earlier Post-COVID-19 Conditions HealthPathway (see Appendix 6) (Taskforce 2021).

3.2 Services developed internationally in response to Long COVID

The range of emerging services offered in selected countries for patients with Long COVID are summarised in Appendix 7. These services are typically not yet widespread and therefore access often remains limited. Most involve some form of multidisciplinary clinic model offering different combinations of assessment, treatment and rehabilitation services. Support groups, advocacy groups and online resources for Long COVID patients are also emerging in badly affected countries, often independently of formal health services. These include:

- the Long Covid Support Group (2020), with members of around 39,000 around the world;
- Doctors in Distress (2020) hosting webinars for doctors and other healthcare professionals to share their experiences related to Long COVID in the UK;
- Long COVID Physio (2020) supporting physiotherapists and support workers created to be access globally;
- Long COVID Alliance (2020) providing an avenue for different stakeholders to collaborate and share knowledge related to Long COVID in the US; and
- Long COVIDSOS (2020) providing resource and international support group links through partner organisations.

There are also Long COVID support groups found in Australia. Covid-19 Australia Survivors Support (2020) has 121 members and the Long Covid Asia-Pacific Support Group (2020) includes 329 members residing in the Asia Pacific region. Other support groups around the globe are noted elsewhere (Long COVID Support n.d.)

A common theme in the rapidly emerging literature on Long COVID care is the need to involve people with Long COVID in the design of services and for their voices to be taken seriously. Many report being disbelieved or having their symptoms dismissed by health practitioners, and the combination of this “testimonial injustice” (disbelief and dismissal) with inadequate care guidelines can result in failure to diagnose and to offer adequate care (Pantelic & Alwan 2021).

3.3 Long COVID policy, governance and research in Australia

As Australian and state and territory governments move to consider Long COVID more directly, higher-level system governance and policy on Long COVID is beginning to emerge. The NHMRC’s National COVID-19 Health and Research Advisory Committee provided some early advice on Long COVID during 2020. The Australian Government has sought consumer representatives to be part of a *Supporting Long COVID Advisory Group*. The National COVID-19 Clinical Evidence Taskforce has developed a flowchart for post-acute COVID-19 management (Taskforce 2021).

Australia is part of the Australasian COVID-19 Trial (ASCOT) ADAptive Platform Trial (ASCOT ADAPT) for moderately severe admitted cases of COVID-19 investigating the use of therapeutics (including the steroid dexamethasone, the broad spectrum antiviral remdesivir and the disease modifying, anti-rheumatic hydroxychloroquine), physical and psychologic rehabilitation services (ANZCTR 2020).

There are also long-term studies being undertaken. The “long-term biological physiological, and psychological impacts of COVID-19 infection on a regional population” is being investigated at

Barwon Health (Barwon Health 2020). Monash University is investigating the long-term mental and brain health impacts of COVID-19 (Monash University 2020). The University of Adelaide is investigating postural orthostatic tachycardia syndrome (POTS) in Long COVID syndrome (ANZCTR 2021b); and St. Vincent's Hospital Sydney is investigating persistent symptoms of COVID-19 and home-based virtual rehabilitation for Long COVID (ANZCTR 2021a; Darley et al. 2021b).

The Australian Institute of Health and Welfare (AIHW) has stated that it is "...working to develop a national linked COVID-19 registry and research data set that will provide an asset for use in COVID-19 research into the medium and longer-term health effects of COVID-19, including effects on health system use" (AIHW 2021a). However, limited information is available on the scope and content of this planned registry. Funding from government agencies and private organisations has also been made available to support research related to post-acute COVID-19 consequences (Department of Health and Human Services 2021).

3.4 Direct impacts of on the healthcare workforce

The COVID-19 pandemic has also directly impacted healthcare staff. Health workers have been at high risk of infection and consequently a growing number of care providers are living with Long COVID. Care providers also experienced considerable emotional distress during the COVID-19 pandemic, particularly those staff involved in acute care for COVID-19 patients.

According to a systematic review and meta-analysis of 28 non-Australian studies of healthcare workers with COVID-19 (n=119,883 patients), 15.1% of infected healthcare providers were hospitalised and 1.5% died from this disease (Gholami et al. 2021). Another systematic review and meta-analysis, analysing 97 articles, reported that approximately 0.5% of healthcare workers infected with COVID-19 died because of disease complications (Gómez-Ochoa et al. 2021). According to the International Council of Nurses (ICN), approximately 1.6 million healthcare workers have been infected with COVID-19 across 34 countries as of 31 December 2020 and based on their analysis, an estimated 10% (0-15%) of all confirmed cases are healthcare workers (ICN 2021). Given the emerging evidence on Long COVID, a percentage of these infected healthcare workers will have developed prolonged symptoms; and a group of healthcare professionals have already reported their experiences with Long COVID (Gorna et al. 2021; Ladds et al. 2020). Recent ONS data found that the prevalence of Long COVID was higher among UK health care workers than in other employment sectors (ONS 2021a). Some health workers reported that they have not fully recovered to their previous health and could not return to work (Gorna et al. 2021).

The mental health of healthcare workers has also been impacted by the pandemic, with potential long-term consequences. In the UK, a survey examining the mental health of healthcare workers undertaken during the first wave of the pandemic found that almost half of the respondents (45%, n= 322/709) reported symptoms of probable PTSD, severe depression, or anxiety disorder (Greenberg et al. 2021). In response to this burden, there are evolving demands and a call to list COVID-19 as an occupational disease as it threatens the health of workers and has significant implications on income from the day that they acquire the disease to the point of their death (ICN 2020; Limb 2021).

An Australian study of hospital clinical staff has shown approximately a quarter of the nurses, midwives, doctors and allied health staff surveyed during the first wave of the pandemic reported symptoms of psychological distress. Nurses and midwives had significantly higher levels of anxiety, depression and stress compared to data from Australian adults before the pandemic. They also had more severe anxiety symptoms than medical and allied health staff working in the same health service. Having less clinical experience and direct contact with people with a COVID-19 diagnosis made staff more vulnerable to distress (Holton et al. 2020). The WHO has released a Charter dedicated to healthcare worker safety as they recognised the burden of COVID-19 and its prolonged symptoms for healthcare providers (WHO 2020d).

Healthcare systems will be further challenged with the reduced healthcare capacity resulting from the events caused by COVID-19, a growing number of healthcare workers with Long COVID, work-related stress, unmet backlogs from delayed procedures and services, and ongoing healthcare demand from the general population.

4 Value-based Healthcare and Long COVID

4.1 The challenge of Long COVID in Australia

From a health system perspective, Long COVID and the long-term clinical sequelae of COVID-19 will present a number of complex challenges. Leaving aside the ongoing prevention and management of COVID-19, managing the pandemic's long-term sequelae will require healthcare systems to address three intersecting areas of patient need (Figure 4).

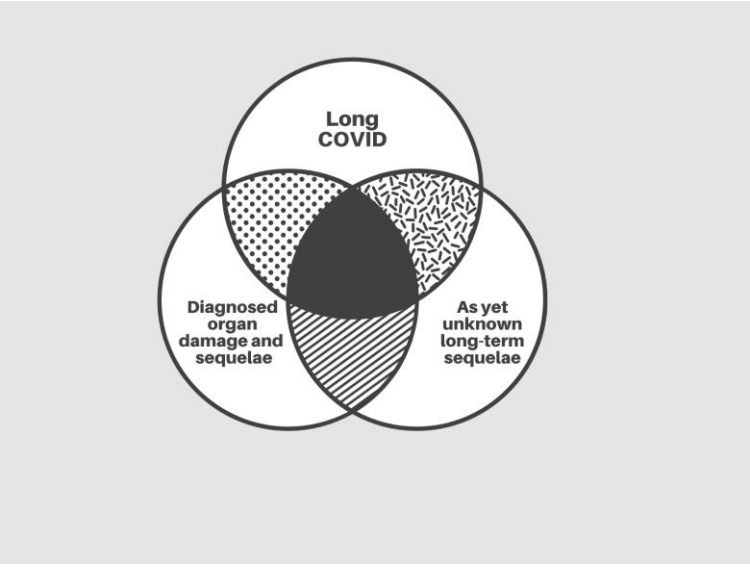


Figure 4. Long-term healthcare needs due to post-COVID-19 sequelae

An outcome focused, value-based health care approach that that reflects contemporary governance and funding arrangements will be necessary for:

- Achieving the effective, patient-centred management of Long COVID, a serious and debilitating condition for which there is no simple or definitive treatment.
- Managing the potential clinical evolution of patients who may have suffered organ damage and impairment due to COVID-19, while balancing the competing risks of inaction and overdiagnosis.
- Preparing proportionately for the possible emergence of other, as yet unknown, post-COVID sequelae (especially neurological conditions) such as those seen after other viral pandemics.

This challenge is exacerbated in Australia precisely because COVID-19 cases have, to date, been low. The Australian response to Long COVID needs to be proportionate: suitable for dealing with today's relatively small numbers, yet capable of rapid scaling-up if circumstances required it.

In Australia, as of April 2021, it is estimated that there is around one Long COVID case for every five to ten GPs (Table 3). If Australia can avoid further large outbreaks, this means that most Australian GPs will probably never see a patient with Long COVID. Even in Victoria, where COVID-19 case numbers were highest, there is likely to be less than one Long COVID case for every two GPs statewide. To date, 91.2% of confirmed Victorian COVID-19 cases were concentrated in Greater Melbourne, with only 8.8% in regional Victoria (Department of Health Victoria 2021), while 79.6% of the GP workforce is based in Greater Melbourne and 20.4% in regional areas. This would still suggest an average of less than two Long COVID cases for every three GPs across Greater Melbourne (accepting that some greater local clustering will have occurred). This poses significant questions as to how well GPs might be able to assimilate knowledge, correctly diagnose and offer best care to a small group of patients presenting with a new condition – especially when what constitutes the optimal clinical management of these patients remains far from settled. It is possible that a small number of GPs might have attracted larger numbers of Long COVID patients through formal or informal referral networks, but data on the extent to which this may have occurred are not currently available.

Table 3. Estimated Long COVID cases per registered General Practitioner.

		Long COVID Cases per GP FTE	
State / Territory	**GP FTE***	**Lower**	**Upper**
ACT	396.2	0.03	0.06
NSW	9764.9	0.05	0.10
NT	231.1	0.05	0.09
QLD	6390.3	0.02	0.04
SA	2053.9	0.03	0.06
TAS	566.4	0.04	0.08
VIC	7612	0.26	0.50
WA	2839.1	0.03	0.06
Total	29853.9	0.10	0.18

Source: Department of Health, General Practice Workforce providing Primary Care services in Australia 2019 (Calendar Year). * General Practitioner Full Time Equivalent.

Developing quite complex multidisciplinary care models for relatively small numbers of patients, dispersed across the country, is also likely to be challenging. Yet this challenge is not unprecedented. It exists, for example, in achieving effective coordination of care for patients with less common chronic conditions in rural and remote areas. However, some of the more discouraging experiences reported by people with Long COVID, such as inability to diagnose, disbelief or dismissal (Pantelic & Alwan 2021) have also been reported in certain other chronic conditions, especially ME/CFS (Cullinan et al. 2021). Effective advocacy by patients has achieved greater understanding and acceptance by health professionals in other conditions, most notably HIV/AIDS.

Australia remains in the fortunate position that our most important strategy for Long COVID unquestionably remains aggressive primary prevention of SARS-CoV-2 infection and COVID-19 illness. A truly successful VBHC approach for Australia means that Long COVID cases and long-term consequences will be minimised, and not allowed the opportunity to become a significant challenge for the health care system.

Population-based success will inherently limit the number of long-term COVID cases– but this success is itself likely to preclude the large-scale development of clinical expertise in managing Long COVID in this country. VBHC approaches can contribute to future management of Long COVID building on existing knowledge around how to provide effective, integrated care for people with chronic conditions. Indeed, effective approaches to Long COVID will themselves potentially provide new insights on how to manage complex multimorbidities in the future (Sivan, Rayner & Delaney 2021).

4.2 More than clinical outcomes

Prior to the discovery and widespread recognition of “Long COVID”, patients with prolonged COVID symptoms were hoping for a “full recovery of health". However, many experienced limited access to care and often faced a lack of empathy and dismissive behaviour from many healthcare providers (Honigsbaum & Krishnan 2020; Kingstone et al. 2020; Ladds et al. 2020). For COVID-19 survivors, recovery is not merely about surviving a potentially lethal disease, but also regaining their full health and improving their experiences of healthcare (Wardill 2021).

By embracing value-driven care, three dimensions of health outcomes, described in value-based health care literature could be achieved:

- “**capability**: ability of patients to do the things that define them as individuals and enable them to be themselves,"
- "**comfort**: relief from physical and emotional suffering" and
- “**calm**: ability to live normally while getting care” (Teisberg, Wallace & O'Hara 2020).

Inability to achieve these dimensions of health outcomes would result in a distorted quality of care and unmet patient needs that may in turn progress to a more complex disease state; leading to an increase in healthcare spending (Teisberg, Wallace & O'Hara 2020). The inability to measure the outcomes that matter to patients would lose the most powerful tool for reducing costs (Porter & Lee 2013).

In the context of COVID-19, the outcomes that matter to patients can be tracked and measured using a range of standard outcome measures. For example, the COVID-19 Standard Set (C19-SS) developed by the International Consortium for Health Outcomes Measurement (ICHOM) follows a patient's health outcomes during recovery from COVID-19, considering dimensions such as "social and mental functioning, quality of life, symptoms and clinical outcomes" (Figure 5).

These Patient Reported Outcome Measures (PROMS) can be collected in all levels of healthcare settings for a period of three months following patient's hospitalisation for COVID-19. The tool can also continue to be used for longer periods, depending on the patient's recovery. Data collected from C19-SS can be used to inform quality improvement in different healthcare services (ICHOM 2020).

Long COVID offers a rare opportunity to build entirely new services and models of care, which place patients at their centre from the outset, and can start with consideration of those outcomes that are most important to these patients.

Figure 5. ICHOM COVID-19 Standard Set (ICHOM 2020).

For example, the emerging literature on patients' lived experience of Long COVID reports that many people are encountering "testimonial injustice" – that is, not being believed or taken seriously by health professionals, leading to stigmatisation and compounding distress (Pantelic & Alwan 2021). However, co-designing a patient-centred COVID-19 perspective involving participation and cooperation between patients and health care providers, with strong clinical leadership, strong patient leadership, and robust governance will align with patient needs, resulting in better treatment plans and lead to more favourable outcomes (Gafanovich 2019).

Patient-centred care approaches such as improved practitioner communication, shared decision making, and technology-enabled decision and information aids will be important for underpinning effective patient-centred care that people with Long COVID require. However, as the burden of COVID-19 shifts the focus from 'what is the matter with people' to 'what matters to people'' (WHO 2021b), the outcomes that matter to patients with Long COVID are likely to also encompass a much broader range of factors than purely clinical outcome measures. This will most likely yield important lessons for other chronic conditions, including for ME/CFS, which shares several features with Long COVID.

For example, an inability to return to work is a key feature of prolonged Long COVID; this has devastating and immediate financial consequences for low paid, insecure or casual workers

(especially temporary residents with limited or no access to Medicare and social protection systems in the Australian context), but may be an issue even for well-paid medical professionals (Ziauddeen et al. 2021).

Employment protection, disability and income support are significant issues for any attempt to achieve holistic VBHC outcomes for people with Long COVID. Early evidence suggests that inadequate rest in the first two weeks of infection may predispose to the development of Long COVID (Ziauddeen et al. 2021). Therefore, a lack of access to paid sick leave for casual and gig economy workers – itself an important issue earlier in the pandemic as a factor making it hard for people to self-isolate – may also prove a further disadvantage if workers are at increased risk of subsequent Long COVID.

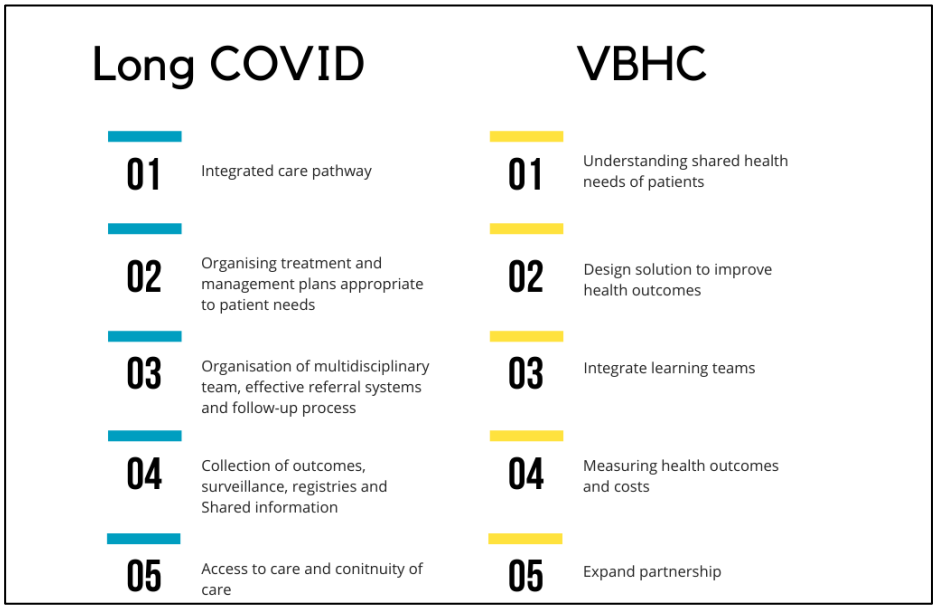
The importance of recognising the role of the social determinants of health in promoting health outcomes will be critical to managing Long COVID; and multisectoral policy interventions will be required to achieve the best possible outcomes for patients.

4.3 VBHC and Long COVID

Given the complex and cyclical nature of COVID-19 sequelae, an efficient, holistic and integrated care approach providing targeted interventions that meet survivors' needs will be required to treat and manage Long COVID illness (Gorna et al. 2021; Sivan et al. 2020; Wong et al. 2020).

Integrated, patient-focused care is one of the main components of VBHC encompassing services like "diagnosis, treatment, recovery, rehabilitation, prevention, long-term monitoring and management of chronic conditions" (Woolcock 2019). In this respect, the healthcare needs of patients with Long COVID align with Porter and Teisberg's principles of value-based healthcare (VBHC) (see Figure 6).

Figure 6. The needs of patients living with Long COVID and the core concepts of VBHC[3].



[3] Five point strategic framework for VBHC implementation adapted from "Defining and Implementing Value-Based Health Care: A Strategic Framework" by Teisberg, Wallace and O'Hara (2020). Long COVID themes developed by the authors.

For example, five themes arise from the literature describing the models of care that are needed for patients living with Long COVID (Figure 6):

- structuring integrated care models for Long COVID patients;
- acknowledgement of patient's narrative and organising treatment and management plans appropriate to patient needs (Greenhalgh et al. 2020; Honigsbaum & Krishnan 2020);
- organisation of multidisciplinary teams, effective referral systems and follow-up processes (Sivan et al. 2020);
- enabling the collection of health outcomes and long-term follow up though surveillance system or registries to gain knowledge of the disease course and sharing information to improve disease management (Alwan 2021; Dennis et al. 2020; Gorna et al. 2021)
- ensuring access to care and continuity of care (Ladds et al. 2020).

While a VBHC approach to providing care for Long COVID patients starts with the "understanding of shared health needs of patients" (Teisberg, Wallace & O'Hara 2020) it also requires organising care around these patient segments. For example, patient segments can be used to deliver targeted programs of integrated care to Long COVID patients with high levels of needs; and can also support more comprehensive health strategies by ensuring that the health care needs of population groups in their entirety are considered. This would enable providers to design and deliver solutions that meet the needs of the patient segment, as well as considering their non-clinical needs, which when left unmet, undermine the health outcomes that can be achieved (Teisberg, Wallace & O'Hara 2020).

Long COVID may offer an opportunity to trial new approaches to achieving better coordination of multidisciplinary teams and collaboration across organisational boundaries and between public and private sector practitioners. However, the existing architecture of the Australian healthcare system means that this cannot be achieved by simply setting up new, specialist referral "Long COVID Clinics". Instead, the formation of "integrated learning teams" which promote collaboration between care providers from different disciplines and allow practitioners to work to the top of their scope of practice can provide an avenue for individual practitioners to think, learn together and co-develop management plans to improve and personalise care for Long COVID patients. Nurturing such innovations for Long COVID care could reap substantial spin-off benefits if lessons can be learned which might improve care coordination of other major chronic conditions.

There is a need to understand the costs associated with the care of people with Long COVID and the measurement of cost and outcomes that matter to patients would enable quality measurement, benchmarking, and improvement of care services. Value-based health care approaches can support sustainable health care reforms that explicitly identify Long COVID as a cost when evaluating pathways of care, for example, patients recovering from COVID-19 who require follow-up physical assessments (Paneroni et al. 2021).

The collection of patient-reported outcomes is not a standard practice yet across Australia, and patients' voices are not routinely taken into consideration in designing treatment plans. Information technology platforms are fragmented, preventing efficient and collaborative communication

between healthcare providers. Surveillance systems are not tracking ill-health and long-term consequences of COVID-19 (Kingstone et al. 2020).

Outcome measurement would enable research and development of treatments for patients experiencing symptoms with limited or no cure. Despite standard measurement tools being available (for example, the ICHOM COVID-19 Standard Set), Australia's data collection and sharing architecture does not support some of the large-scale approaches to research and surveillance available to some healthcare systems (for example, Scotland, England). The rapid development of dedicated COVID-19 or Long COVID registries might offer a pragmatic short-term solution, allowing capture and surveillance of key epidemiological, resource and outcome measures across Australia.

Healthcare systems around the globe have long been challenged to implement an integrated multidisciplinary approach to deliver holistic care for patients with complex problems (such as long-COVID) (Ayoubkhani et al. 2021b; Geberhiwot, Madathil & Gautam 2020). The Australian healthcare system is not currently well-designed, structured or incentivised to support an integrated care model, and it does not have an effective national strategy to catalyse integrated care practices and patient-focused care (Woolcock 2019). However, displaying and providing evidence of improved outcomes would generate opportunities to expand partnerships and enable teams to provide care for more people (Teisberg, Wallace & O'Hara 2020)

The COVID-19 pandemic has demonstrated that much of the capability, competencies and leverage for effective stewardship and governance in the Australian healthcare system lies at state and territory level – yet primary care funding and management remains a Commonwealth responsibility. Like most healthcare systems, Australia does not have effective mechanisms in place to enable a robust and simple follow-up process for patients with chronic or complex conditions (Geberhiwot, Madathil & Gautam 2020; Ladds et al. 2020). That is, the healthcare system lacks the necessary components that would help to meet the needs of Long COVID patients; and requires the development of new care and coordination models.

VBHC approaches potentially offer better solutions to provide high-quality care for patients, living with COVID. Strategic priorities such as the implementation of innovative funding models and measurement of outcomes that matter to patients, as agreed under the 2020-2025 Addendum to the National Health Reform Agreement (Council on Federal Financial Relations 2020a) are well aligned with the models of care required to support people with Long COVID.

4.4 Embracing and accelerating VBHC concepts

International studies show that COVID-19 post-acute care pathways reflect concepts of the VBHC integrated care model. For example, the community-based COVID-19 rehabilitation pathway in the United Kingdom highlights the importance of screening and an effective referral scheme for COVID-19 survivors (Sivan et al. 2020). The objective of the model is to deliver healthcare services to COVID-19 survivors that are most suited to their conditions. In the pathway, both hospitalised and non-hospitalised COVID-19 survivors enter the model and are screened using the COVID-19 Yorkshire Rehabilitation Screen (C19-YRS) tool which screens the long-term health problems of patients who

have had COVID-19. These patients are then referred remotely to a community-based rehabilitation centre: either to a COVID-19 multidisciplinary team (C19-MDT) or to a single discipline. Patients with improved symptoms have the option to undertake self-management activities, access online rehabilitation resources or use smartphone rehabilitation applications (Sivan et al. 2020). In the model, a clinician (pathway coordinator) ensures that patients with complex cases are introduced to the C19-MDT team. They also coordinate patients' care across the services (Sivan et al. 2020).

A similar model called the "COVID recovery outpatient service" has also been established to organise essential health services and rehabilitation for patients diagnosed with COVID-19 pneumonia (O'Brien et al. 2020). The model is a mix of virtual and face-to-face modes supported by a multidisciplinary team including respiratory, critical care, infectious diseases, psychiatry, and psychology services (O'Brien et al. 2020). The model aims to provide a high quality of care, prevent over-investigation and duplication of health services, and decrease waiting times (O'Brien et al. 2020).

Both models note the use of health outcome measures such as the 36-Item Short Form Health Survey (SF-36) to collect changes in patients' health condition and capture the effect of the intervention (O'Brien et al. 2020; Sivan et al. 2020).

Integrated care models such as these go further than existing Australian care pathways in organising and ensuring access to multidisciplinary care for Long COVID. Even the Victorian COVID-19 Positive Care Pathways program, which encompasses primary, community and acute care, is still focused more on initial management of COVID-19 cases following diagnosis than on long term care. The expansion of these pathways to incorporate elements used in UK COVID care pathways, including proper screening and assessment, and a role for central clinical care coordinators in managing access to multidisciplinary specialist inputs, is required.

In a Canadian study, patient reported outcome measures (PROMs) were used for patients who were diagnosed with COVID-19 three months post the initial symptom onset (Wong et al. 2020). PROMs are standardized validated tools to provide information regarding the perceived functional well-being and health status of the patient and capture dimensions such as symptoms, quality of life, functionality, physical, mental and social wellbeing (Wong et al. 2020). The study indicated that among 78 COVID-19 survivors, 76% reported that they have at least one abnormal PROM and a third had a moderate impairment in major dimensions of life (Wong et al. 2020); and showed that PROMs are valuable tool to capture various aspects of health from the perspective of the patient. It was also noted that PROMs are useful for clinical decision making, development of discharge pathways and improving the alignment of the health system to patients' needs (Wong et al. 2020).

PROMs for patients with Long COVID are providing a comprehensive picture of the patient's experience post-acute illness and collected data is a valuable tool in developing care management plans for use by interdisciplinary teams (Romeyke, Noehammer & Stummer 2020).

5 A value-based strategy for Australia

The COVID-19 pandemic is dynamic, highly uncertain, and far from having stabilised in the Australian health sector. The low numbers of people infected with COVID-19 to date in Australia could change rapidly if control measures were to fail. Therefore, it will be important for governments to develop a workable strategy to ensure that those who will suffer longer-term health consequences from COVID infection can be well-treated and cared for in the months and years to come.

Australia's response to managing the long-term sequelae of COVID-19 should be guided by the principles of value-based health care and reflect scale and proportionality, with the ability to adapt quickly to changing circumstances. In the best case, a strategy to manage the health needs of some thousands of COVID-19 survivors is required, but at worst, the ability to expand rapidly is needed should Australia suffer a large new wave of infections. It should also be seen as a precautionary investment for the future, to ensure that the as-yet unknown long-term health burdens and consequences of COVID-19 can be recognised as early as possible, and managed as well as possible, should they emerge over time. The key themes raised in our analysis of the long-term challenges posed by COVID-19 to the Australian health care system, are mapped against the "four pillars" of VBHC (EXPH 2019)(Table 4).

Table 4. Key considerations for a VBHC strategy for long-term post-COVID care in Australia.

VBHC Pillar	Implications for managing long-term sequelae of COVID-19
Personal value	• All Long COVID patients require access to sensitive and appropriate multidisciplinary care and support, that does not dismiss but rather seeks out and responds compassionately to their concerns and experiences, within the context of there being no definitive treatment for Long COVID. • Patients with PICS and longer-term organ impairment need careful monitoring to ensure they receive the right care, but without exposing them to risks of overdiagnosis and unnecessary treatment. • Measurement of outcomes requires careful attention to experience and non-clinical outcomes.
Technical value	• Relatively low case numbers in Australia suggest that best technical value might be achieved by a very small number of specialised centres providing guidance, authoritative information and oversight to support local practitioners and services who will be unlikely to develop substantial expertise. • New approaches to effective care coordination will be needed to overcome the historical precedents of fragmentation and inertia. • Investment in effective, active surveillance at scale is necessary to monitor for the emergence of as yet unknown sequelae.

	• However, surveillance and monitoring (especially in relation to organ damage) must carefully balance the need for monitoring with the risks of overdiagnosis, 'incidentalomas' and resulting harms from overtreatment.
Allocative value	• The greatest population value can be achieved by preventing future cases of COVID-19. • The population of relevance for any VHBC approach to long-term post-COVID care is all Australian residents who have been infected with SARS-CoV-2, not the patients of specific specialised health care providers or organisations. This population must be given a real voice in decisions. • The inequities in access common across Australian health care (for example, poorer access in regional / rural areas, poorer access for lower socioeconomic groups, Aboriginal and Torres Strait Islander people, recent migrants etc.) must also be mitigated in post-COVID care strategies. • Dealing with Long COVID offers an important opportunity to develop better strategies for managing other, similar long-term debilitating conditions, most notably ME/CFS; people living with these conditions should also benefit from service improvements to meet the needs of Long COVID.
Societal value	• Ability to work, loss of income, inadequate sick leave and insecure employment have repeatedly proved to be significant in the COVID-19 pandemic and apply equally to those suffering its long-term consequences. A health care strategy that does not address and connect with effective action in the employment and wider social determinants of health will be inadequate and ineffective (AHHA 2020).

6 Recommendations

In parallel to the wider government response to COVID-19, an effective and proportionate value-based response to the longer-term health consequences of COVID-19 in Australia is now required. The four steps outlined in the Australian Healthcare and Hospitals Association, *Healthy people, healthy systems* blueprint for VBHC reforms in the Australian health system (AHHA 2021) provide a useful template for a national strategy on the long-term sequelae of COVID-19. It must be noted however, that the primary prevention of COVID-19 remains at all times the most effective means of mitigating the long-term health consequences of infection at population level.

6.1 A nationally unified and regionally controlled health system that puts patients at the centre.

Long COVID and the effective management of other COVID-19 sequelae present an additional challenge to Australia's ability to offer integrated, well-coordinated and person-centred care. The

relatively limited scale of Long COVID seen in Australia to date means that it is not realistic to expect its emergence alone to exert sufficient pressure on the system to overcome these long-standing problems.

However, Long COVID does provides an opportunity to test new approaches to care coordination and integration that – if successful – will have much wider applicability. In this regard, long-term post-COVID care provides impetus to the need for an alternative approach, which could include a new care coordination function in state and territory health departments and/or public health services. This would support patients, primary care providers and specialists to access the most appropriate range of services across both public and private sectors by actual or virtual pooling of hospital and Medicare funding for relevant services.

6.1.1 Establishing a national post-COVID Centre of Excellence and state-based care coordination centres

A national specialist post-COVID Centre of Excellence should be established to provide guidance, authoritative information and oversight to support local practitioners and services, providing a limited referral service for the most complex cases only. Strong engagement with international networks will maximise access to emerging international evidence.

Statewide care coordination centres should be established to mobilise public and private resources to provide support to patients and care providers and to ensure that Long COVID patients have effective local access to multidisciplinary care (including primary care providers and consultant physicians for any necessary acute care). Monitoring and management of patients known to have suffered specific organ damage should be undertaken by a designated public hospital referral centre in each state or territory, with patients referred via the state care coordination centre.

Statewide care coordination centres should be enabled to trial pooled funding models and strategic purchasing that, subject to evaluation, could also be applied more widely to the management of chronic disease conditions.

In the event of future outbreaks and larger case numbers, care coordination centres could be reviewed and scaled up as necessary. Much larger case numbers (for example, on the scale seen in the UK) would warrant the establishment of regional specialised treatment and management centres to provide large scale referral and multidisciplinary care, and the establishment of coordination centres at Local Health Network level rather than at state or territory level. Careful attention should be paid to the efficacy of specialised service models in other countries, so that service models in Australia can be rapidly revised if the evidence or the situation changes.

6.2 Performance information and reporting that is fit for purpose.

Given their novelty and uncertainty, Long COVID and the long-term sequelae of COVID-19 are particularly well-suited to the application of the WHO's "3D" approach to priority setting for value-based health services: Data, Dialogue and Decisions. This approach requires health planning and funding authorities to search for reliable data for robust, evidence-based analysis. Data are then used to inform a deliberative dialogue process with key stakeholders (COVID survivors and people

living with Long COVID), allowing decisions on priorities, actions, and resource allocation (WHO 2021b).

6.2.1 Establish a nationwide COVID-19 data registry

An effective nationwide registry that combines patient-level data on COVID-19 and subsequent health and healthcare utilisation history is an essential requirement for effective population-level management of Long COVID in Australia; and for ongoing surveillance of the evolution of other clinical sequelae. The Australian healthcare data architecture and infrastructure does not yet support the levels of data integration and linkage seen in some high-income healthcare systems, making it necessary to develop a purpose-built data asset. The AIHW's current work in this area is therefore essential, but must cover the full range of functions that have been identified, and should incorporate:

- state and territory SARS-CoV-2 testing results and contact tracing datasets (subject to any legislative constraints on re-use of these data); and
- data on all individuals who have returned a positive test result (including testing conducted in the private sector).

This would allow large-scale population surveillance of the health status of people who have been infected with COVID-19, driven by an active contact and follow-up process to seek consent to participate, and with a significant role for patients themselves in providing data. It would also allow case-finding of Long COVID patients who are not receiving adequate care at present.

The registry would be a key tool in monitoring the emergence of hitherto unknown sequelae in post-COVID patients. The scope of the proposed AIHW COVID registry / dataset should be rapidly reviewed to ensure it can meet these requirements and inform evolving clinical guideline development.

6.2.2 Regularly update clinical guidelines for post COVID care

The National Health and Medical Research Council and the National COVID Clinical Evidence Taskforce should provide regular updated clinical guidelines on the long-term management of post-COVID care to reflect evolving evidence. These guidelines should cover:

- best care for the physical and mental health needs of people living with Long COVID, with a particular focus on multidisciplinary care and rehabilitation to achieve patient-defined goals;
- best practice monitoring of post-COVID patients for long-term sequelae, with a particular focus on minimising the risks of overdiagnosis due to repeated screening.

The development of clinical guidelines should involve extensive co-design with people living with Long COVID, and guidelines, supporting information and other relevant tools for professionals and patients should be communicated widely. Dissemination should not rely solely on traditional models for communicating guidelines and should focus on the importance of actively listening to patients.

6.3 An integrated health workforce that exists to serve and meet population health needs.

Actions to allow the Australian healthcare workforce to meet the challenge of COVID-19's long-term sequelae will be required to enable coordination – of evidence and knowledge, of patient access, and of effective working and communication across organisational and sectoral boundaries.

Long COVID is not sufficiently prevalent in the Australian population for most healthcare professionals to have gained any direct experience of it, however published research on Long COVID and other sequelae is in a period of exponential growth. Effective and authoritative evidence review, guideline development / revision, and active communication to health professionals is a vital priority – and should be put in place within Australia before it is needed at scale.

Health professionals must be supported to work at the top of their scope of practice and provide seamless access to appropriate multidisciplinary care, especially across the complex interfaces of Medicare-funded services, public healthcare systems, and privately insured services. Effective care coordination that supports patients and professionals alike will be essential to achieve this, and plans must be in place to allow rapid scaling-up were COVID-19 control measures to fail.

In the future, these care pathways could be expanded to cover more chronic conditions and to lay the foundation for more effective care coordination and fund pooling as the backbone for integrated care (RACP 2019).

6.3.1 Supporting research to inform future pandemic planning.

Research and modelling on the morbidity burden of Long COVID and post-COVID sequelae in different age and population groups should be urgently commissioned to supplement emerging data on the mortality burden of COVID-19 and associated control measures and to generate robust QALY / DALY estimates. A strong evidence base can not only inform the development of value-based care models that best serve patients with Long COVID and their care providers but will also provide invaluable data on the burden of disease related to a viral pandemic that can be used to shape future pandemic planning work in Australia and globally.

Research that focuses on health policy, health economics and more directly on the effect of COVID-19 on the structure and function of the health system is also urgently needed. This could include the rapid review of the social determinants of health and the adequacy of existing welfare, employment, sick leave and income support measures for patients with long-term sequelae of COVID-19 - ideally alongside a similar review of the adequacy of such measures in supporting people to self-isolate after testing in the early stages of COVID-19. Focus should also include the impact of the pandemic on casual, low-paid, or gig economy workers, and on other vulnerable populations.

Results could form the basis for policy reform proposals to update national health-related employment, welfare and disability policies in the light of lessons learned from the COVID-19 pandemic and Long COVID.

6.4 *Funding that is sustainable and appropriate to support a high-quality health system.*

The costs of Long COVID and other longer-term sequelae of COVID-19 largely represent an additional cost to the system, above and beyond baseline funding needs. Given Australia's successful control of COVID-19 to date, these costs will remain comparatively small – if control is maintained. Overseas experience suggests that, in badly affected countries, the burden of COVID-19 sequelae will be much larger, with potentially substantial implications for funding and resource needs.

However, the Australian and state and territory governments need to consider long-term COVID and the associated additional cost burden into their resource allocation and risk-management decision processes in parallel with policy deliberations on COVID-19 control strategies. This will ensure that the full costs of control failures are incorporated into relevant analyses.

Should another major outbreak occur in Australia, governments must commit in advance to making available the funding needed to manage these longer-term consequences. In addition, given that out-of-pocket expenses constitute a higher share of health expenditure in Australia than the OECD average, and also show a significantly regressive pattern, falling most heavily on low income households (Wagstaff, Eozenou & Smitz 2020) it will be essential to ensure that MBS and PBS benefits adequately support patients living with Long COVID or other sequelae, and that "safety net" and other measures to mitigate out-of-pocket costs for chronic disease management support these patients fully.

Long COVID in particular offers important opportunities to trial bundled payments and/or fund-pooling between federal and state/territory funding streams as part of new approaches to active care coordination.

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Appendices

Appendix 1

The estimates in Figures 2, Figure 3, and Appendix Figure 7, 8 and 9 were extracted based on the targeted literature undertaken in this study. Long COVID (defined as persistent symptoms post-acute COVID-19 infection) was investigated in Google scholar, Medline and PubMed. All studies that 1) included population with a confirmed/diagnosed COVID-19 case, 2) reported proportion of Long COVID for hospitalised or non-hospitalised COVID-19 patients, and 3) provided a total estimate of Long COVID were included in the analysis.

Figure 7. Long COVID prevalence estimates in hospitalised patients

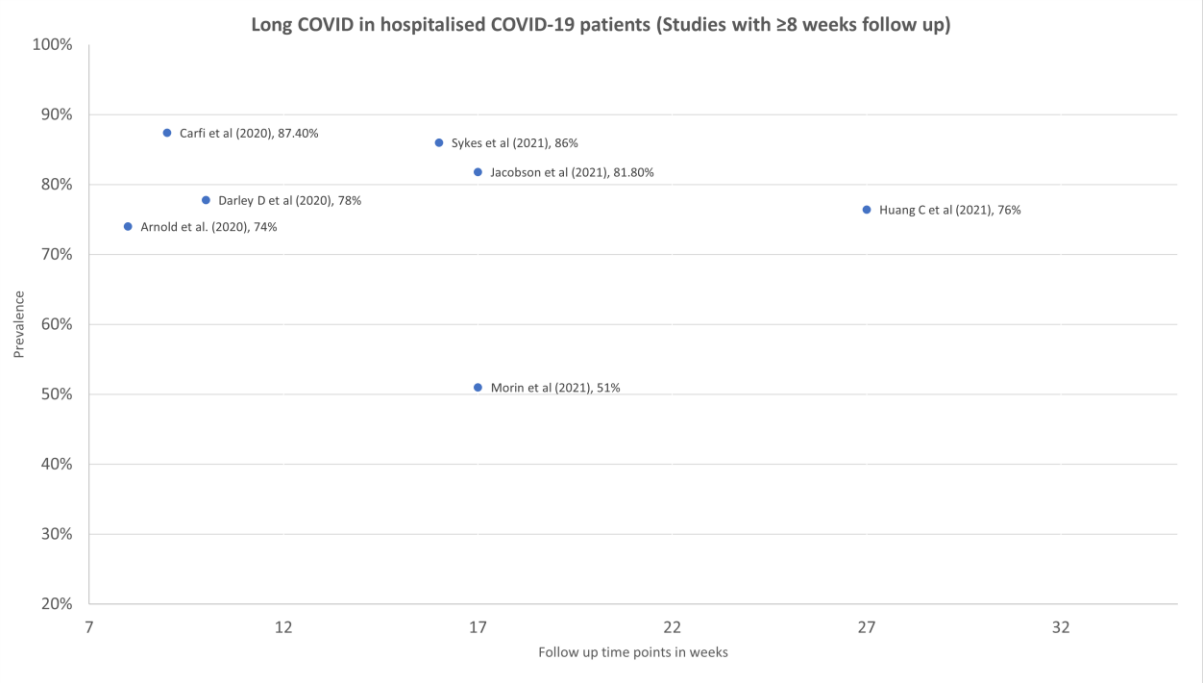


Figure 8. Long COVID prevalence estimates in non-hospitalised patients

Note: Estimates from preprint studies were included

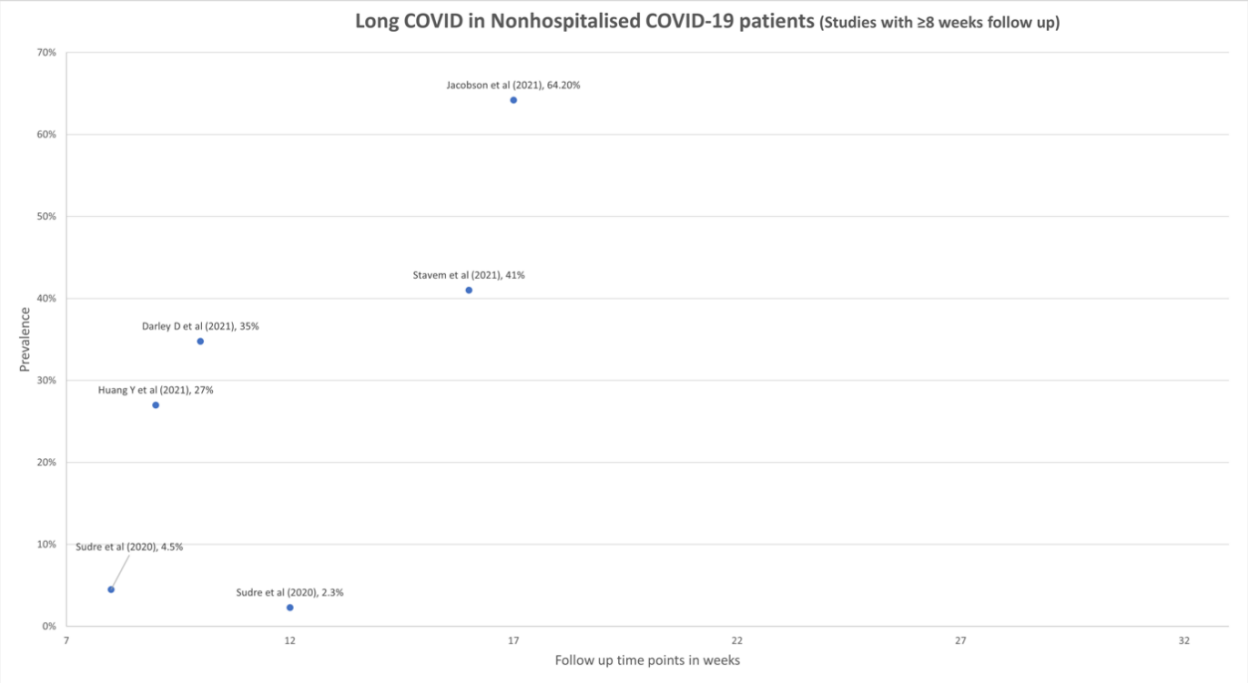
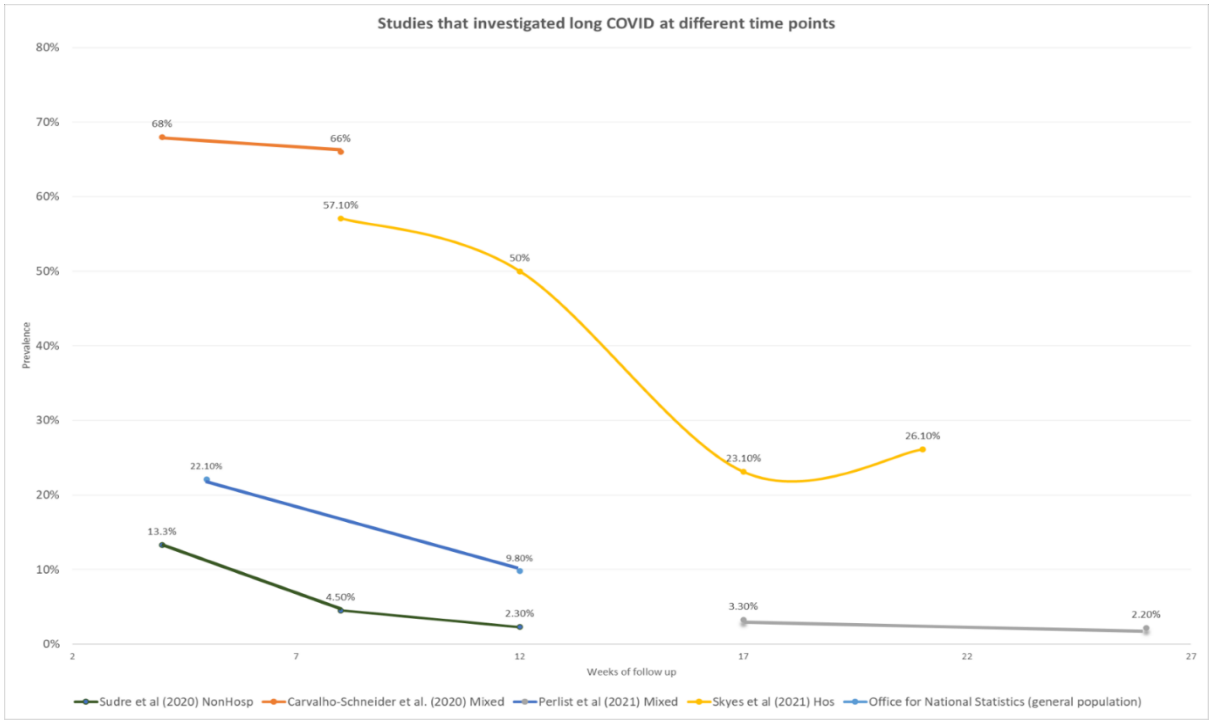


Figure 9. Long COVID prevalence estimates over time in longitudinal studies



Appendix 2

Table 5: COVID-19 infections and deaths in selected countries (15 March 2021).

Country	Sum of Cases - cumulative total	Sum of Cases - cumulative total per 100,000 population	Sum of Deaths - cumulative total	Sum of Deaths - cumulative total per 100,000 population
Global	119,603,761	1,532.14	2,649,722	33.94
United States of America	29,115,662	8,796.20	529,529	159.98
Brazil	11,439,558	5,381.82	277,102	130.36
The United Kingdom	4,258,442	6,272.93	125,516	184.89
France	4,002,129	6,131.32	89,932	137.78
Italy	3,223,142	5,330.87	102,145	168.94
Spain	3,183,704	6,809.37	72,258	154.55
Germany	2,575,849	3,074.39	73,418	87.63
South Africa	1,529,420	2,578.75	51,326	86.54
Netherlands	1,157,192	6,753.43	16,069	93.78
Canada	906,201	2,401.03	22,434	59.44
Belgium	808,283	6,974.20	22,441	193.63
Sweden	712,527	7,055.24	13,146	130.17
Japan	447,906	354.14	8,590	6.79
Denmark	220,459	3,806.13	2,391	41.28
Uruguay	70,133	2,018.95	698	20.09
Singapore	60,105	1,027.38	30	0.51
Australia	29,117	114.18	909	3.56
New Zealand	2,074	43.01	26	0.54

Source: https://covid19.who.int/

Accessed 21 March 2021

Note: These figures (as of March 2021) were used as the basis for the scenarios and counter-factual scenario described in section 2.7. Current figures can be accessed at: https://covid19.who.int/

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Appendix 3

Table 6. Organ Damage and Post-Intensive Care Syndrome

Author, Year	Title	Study type	Participants	Eligibility criteria	Follow-up time	Examination methods	Main outcomes/result	Author's Analysis
Dennis et al. (2020)	Multi-organ impairment in low-1 risk individuals with long COVID	Prospective cohort study	201 low risk individuals, mean age 44, 31% HCW, 18% hospitalized	RT-PCR confirmed, diagnosed by clinicians	4 months post initial symptoms	Validated questionnaires, fasting blood and MRI	"There was evidence of mild organ impairment in heart (32%), lungs (33%), kidneys (12%),liver (10%), pancreas (17%), and spleen (6%). Single (66%) and multi-organ (25%), impairment was observed, and was significantly associated with risk of prior COVID-19 hospitalization ($p<0.05$). "	"one third of low-risk individuals with long COVID syndrome have cardiac impairment in the form of mild systolic dysfunction or myocarditis three months following SARS-CoV-2 infection. Whilst causality cannot be attributed, cardiac function can be viewed as a risk factor for severe infection and an explanation of persistent symptoms in long COVID"
Siow et al. (2020)	Stroke as a Neurological Complication of COVID-19: A Systematic Review and Meta-Analysis of Incidence, Outcomes and Predictors	Systematic review and meta-analysis	Patients who suffered from stroke as a complication of COVID-19. 33 studies with 899 stroke cases over 55,176 patients	NR	NR	CT or MRI scans of the brain Pooled proportions	"The average incidence of **stroke** as a complication of COVID-19 was 1.74% (95% CI: 1.09% to 2.51%). In the included studies, the average age of patients who suffered from stroke(as complication of COVID-19) was 65.5 years. " "The incidence of stroke in COVID-19 patients is relatively low, but increases in certain subgroups such as older population, severely-ill and patients with comorbidities."	"It remains unclear whether stroke is a direct complication of severe COVID-19, or whether it is the consequence of stress in vulnerable populations with less physiological reserves."

Wang et al. (2020)	Clinical symptoms, comorbidities and complications in severe and non-severe patients with COVID-19	Systematic review and meta-analysis	4881 patients diagnosed with COVID in China from 25 studies	Laboratory-confirmed patients with COVID-19	NR	laboratory-confirmed patients with COVID-19.	The prevalence of **acute respiratory distress syndrome** 41.1% (95% CI: 14.1%–68.2%) **acute kidney injury** 16.4% (95% CI: 3.4%–29.5%) **and shock** 19.9% (95% CI: 5.5%–34.4%) in severe patients is higher than the non severe patients with 3.0% (95% CI: 0.6%–5.5%), 2.2% (95% CI: 0.1%–4.2%) and 4.1% (95% CI: _4.8%– 13.1%) respectively.	Not reported
Suh et al. (2020)	Pulmonary Embolism and Deep Vein Thrombosis in COVID-19: A Systematic Review and Meta-Analysis	Systematic Review and Meta-Analysis	3342 patients with COVID	polymerase chain reaction–proven COVID-19			"The pooled incidence rates of PE and DVT were 16.5% (95% CI: 11.6, 22.9; I2 = 0.93) and 14.8% (95% CI: 8.5, 24.5; I2 = 0.94), respectively. " "PE was found frequently in patients who were admitted to ICU "	Not reported
Willi et al. (2021a)	COVID-19 sequelae in adults aged less than 50 years: A systematic review	Systematic Review	31 papers including adults with confirmed COVID		nine days to three months post-discharge from hospital	CT and lung function test	**Respiratory:** Impaired lung function was observed in 19-75% of the study population. 5 studies reported pulmonary fibrosis as a radiological finding 1 study reported hypo perfused ling volume	Even though majority if the patients fully recovered, the authors noted that 'lung damage in the form of residual pulmonary fibrosis persisted in the long term. "
					11 days after quarantine to approximatively three months post-diagnosis.	Cardiac MRI	**Cardiovascular** 3 studies conducted CMRI and found peri-, myoperi- and myocarditis in 3–26% of the participants	"Cardiac damage might be a significant long-term sequelae. " "Even with apparently recovered cardiac function, there might still be a risk of coronary artery disease,

								atrial fibrillation or ventricular arrhythmias as a consequence of myocardial injury “
					after three months 14–90 days after diagnosis of COVID-19 infection	MRI follow-up	**Neurological system and mental health** “MRI follow after three months showed disruptions to microstructural and functional brain integrity and 55% of participants complained about persistent neurological symptoms “ ‘An increased incidence of 5.8% of newly diagnosed psychiatric diseases 14–90 days after diagnosis of COVID-19 infection was shown in a large cohort study in comparison to a control group where 2.5–3.4% of participants received a new psychiatric diagnosis “	“There is widespread speculation concerning neurological long-term consequences. “

Appendix 4

Post-Intensive Care Syndrome

Post-intensive care syndrome (PICS) refers to the "*new or worsening impairments in physical, cognitive, or mental health status arising after critical illness and persisting beyond acute care hospitalisation" (Needham et al. 2012).* It occurs not only to the ICU survivors but also to their family members (PICS-F). According to the American thoracic Society, the signs and symptoms of PICS may presents six month to 1 year post hospitalisation(American Thoracic Society 2020). However, impairments could last for up to 15 years (Biehl & Sese 2020). Sepsis, acute respiratory distress syndrome (ARDS), long duration of mechanical ventilation, delirium, and multiorgan failure are the major key factors for the development of PICS (Biehl & Sese 2020).

It was reported that PICS might developed to half of the patients in critical care (Jaffri & Jaffri 2020). A systematic review and meta-analysis reported that at least 20% of the COVID-19 patients were admitted to the intensive care units (Rodriguez-Morales et al. 2020). In Australia, approximately 19% of the hospitalised patients (14%) were admitted to the ICU (DOH 2021). Given, the number of patients who was admitted to ICU due to COVID-19 it is possible that a large number if COVID-19 patients would be vulnerable to PICS.

Outcomes of PICS

Long-term physical (25% to 80%), mental (8% to 57%) and cognitive (30 to 80%) impairments are common to ICU survivors (Colbenson, Johnson & Wilson 2019). Additionally, one third of patients affected by PICS do not return for work, do not return from their job prior ICU or return to similar pre-ICU salary (Griffiths et al. 2013).

Burden of PICS

It was reported that the mean post-hospitalization cost of ARDS survivors was estimated to be US$43,200 per person. The author noted that the cost burden of COVID- 19 survivors is expected to be higher (Biehl & Sese 2020).

Outcomes of CRITICALLY ILL COVID patients:

- A prospective UK cohort follow 110 patients with confirmed positive PCR result for SARS-Cov-2 for 12 weeks. There were 18 patients who had severe disease, of which 16 required invasive or non-invasive ventilations. They found that health related quality of life scores of patients with severe COVID-19 were low with *deficits in patients perceived ability to perform their physical role and vitality.* The authors recommended a "a post holistic assessment and support"(Arnold et al. 2021).
- A prospective cohort study in France followed 478 COVID-19 patients for four months. Of the 142 admitted ICU patients only 97 consented for assessment. Of which, 53% (51/97) had an invasive mechanical ventilation. Among 94 ICU survivors, anxiety (23%), depression (18%) and PTSD (7%) were observed four months post hospitalisation(Morin et al. 2021).

- In the UK, 43 patients who were previously admitted to ICU were followed 12 to 16 weeks post discharge with a median length of stay of 17.9 days in the ICU. 93% (40/43) of the patients developed severe acute respiratory distress (ARDS).

  The median health utility index (HUS) of 24 patients who attended follow-up was 0.752 (IQR 0.627–0.837). *Fifteen patients were employed pre-ICU. When reviewed at follow-up, 7 (47%) had returned to work and 1 (7%) had taken voluntary retirement. One (7%) patient was planning to return to work in the week following clinic attendance(McCue et al. 2021).*

- A cohort study in Netherlands assessing the respiratory sequalae of invasively mechanically ventilated patients with COVID-19 (n=48), reported that majority of the patients still had abnormal pulmonary function tests and residual changes on the chest high-resolution CT (HRCT) imaging (n=41/48) 3 months post hospital discharge (van Gassel et al. 2021).

Needs

In the article written by Biehl M and Sese D, the following needs were raised by former ICU patients at post-ICU recovery clinic visits (not specific for COVID-19)(Biehl & Sese 2020).

- "Physical and occupational therapy
- Mental health support with referral to counselling, psychology, or psychiatry
- Detailed cognitive evaluation with referral to comprehensive neurocognitive testing as needed
- Medication review and reconciliation, initiation, or discontinuation
- Education of respiratory treatments such as inhalers and nebulizers
- Prescriptions for medical durable equipment
- Coordination of home health services for patients with physical impairments
- Referrals to specialists
- Coordination of care between providers"

Interventions:

Dedicated follow up, should be offered to patients that were on mechanical ventilation for more than 2 days between six and 12 weeks post hospital discharge(Colbenson, Johnson & Wilson 2019). Most of the studies strongly recommend integrated rehabilitation to include psychological, physical and cognitive (Colbenson, Johnson & Wilson 2019; Griffiths et al. 2013; Stam, Stucki & Bickenbach 2020). Some also recommended an adequate screening (Jaffri & Jaffri 2020). Different healthcare professionals from different backgrounds such as physical therapists, occupational therapists, psychologists, nutritionist and physical medicine and rehabilitation physicians (physiatrists) may come together to develop strategies to treat the complications arising from ICU stay (Jaffri & Jaffri 2020). Some also recommended individualised exercise programs to increase strength and balance along with good nutrition(Jaffri & Jaffri 2020). Awareness and education for patients as well as family members and carers were noted as critical components in managing these patients(Jaffri & Jaffri 2020). Patient recovery support groups were also recommended for these patients (Colbenson, Johnson & Wilson 2019; Griffiths et al. 2013)

A scoping review of pulmonary rehabilitation (PR) for COVID-19 patients reported that PR should be started at the start of inpatient-stay when the patients are stable and continued at outpatient service. They also reported that PR may not be similar for all COVID-19 survivors as mechanisms depend on the degree of lung injury and cardiac health. The authors concluded that PR could be safe in COVID-19 patients but needs to be tailored and led by a multidisciplinary approach (Siddiq et al. 2020).

Appendix 5

Table 7: Emerging Long COVID Guidelines

Services needed	Guidelines	Summary	References
Identification of people with ongoing symptom(s) **Or** **Recognition**	NICE, SIGN, RCGP, WHO	Guidelines emphasize clear messaging and provision of comprehensive information related to new and ongoing symptoms for all suspected and confirmed cases of COVID-19. This ensures patient awareness and understanding of symptoms that will facilitate them in determining when and where to ask for help. This includes counselling related to acute life-threatening complications. Initial consultation is recommended for patients who are concerned with new or ongoing symptoms.	(Shah et al. 2021; WHO 2021a)
Holistic assessment after the acute phase of COVID-19	NICE, SIGN, and RCGP	Recommends undertaking complete clinical history for those who had acute COVID-19. Guidelines emphasise the need for healthcare workers to listen to patient's narrative especially on how COVID-19 impacted their ways of life, activities, and their experiences of their symptoms. Healthcare workers are advised not to predict patient's likelihood of developing Long COVID, and caution is noted on the assessment of ongoing versus prolonged symptoms.	(Shah et al. 2021)
Appropriate investigation and referral	NICE, RACGP, SIGN, and RCGP	Depending on patient's condition, investigations or tests are to be given to rule out serious and urgent illnesses, evaluate symptoms, and identify new and unrelated diagnosis. Guidelines state that there is no standardised set of investigations due to the complexities of Long COVID symptoms. However, blood tests, chest radiograph at 12 weeks after acute COVID-19, exercise tolerance test, lying and standing blood pressure and heart rate recordings, referrals to acute services or multidisciplinary	(RACGP 2020; Shah et al. 2021)

		rehabilitation are recommended according to patients' condition or state.	
Shared decision making with treatment plan	NICE, SIGN, and RCGP	Shared decision making on a care treatment and management plan between care provider(s) and patients is recommended. Depending on patient's condition, discussions related to self- or supported management (integrated and coordinated primary care, community, rehabilitation, and mental health services, integrated multidisciplinary assessment service, and specialist care for specific complications) are encouraged.	(Shah et al. 2021)
Management	NICE, SIGN, RCGP, WHO	Management is dependent on patient's condition. Prompt care should be given for patient with life threatening conditions. Otherwise, patients should be advised on self-management. Recommendations include education on Long COVID, advice on self-management strategies, direct patients to support groups and other services (social care, housing, financial support), support patients in discussing conditions with their respective organisations (eg phased return for work/studies). Guidelines also recommend using tools to monitor symptoms such as symptom diaries and symptom tracking apps. A rehabilitation plan designed by a multidisciplinary (MDT) rehabilitation teams was also highlighted with emphasis on physical, psychological, and psychiatric aspects. Management of fatigue is also noted as a key concept of the rehabilitation plan.	(Shah et al. 2021; WHO 2021a)
Follow-up and monitoring	NICE, SIGN, RCGP, RACGP, WHO	Guidelines recommend shared decision making on the agreed number of follow-up and monitoring consultations with the healthcare workers, and patient's preference on the care setting (either remotely or face-to-face mode). Individualised or personalised	(RACGP 2020; Shah et al. 2021; WHO 2021a)

		monitoring per patient's symptoms is also recommended.	
Shared information and continuity of care	NICE, SIGN, and RCGP	The organisation of mechanisms that will facilitate data exchange and integrated working between services such as multidisciplinary meetings is recommended. Also, it is advised that patients be given a copy of their care plans, records, baseline and ongoing measures to keep. Continuity of care is encouraged via a care co-ordinator or a single point of contact.	(Shah et al. 2021; WHO 2021a)
Service organisation	NICE, SIGN, and RCGP, WHO	Guidelines recommend the provision of a coordinated pathway allowing for access to and delivery of multidisciplinary services, including primary care providers, specialists, MDT rehabilitation team, mental health, psychosocial providers, and social services. The need for a clear referral pathway between services is highlighted. It is recommended that a range of delivery methods be offered such as face to face, telemedicine etc.	(Shah et al. 2021; WHO 2021a)

NICE National Institute for Health and Care Excellence, *SIGN* Scottish Intercollegiate Guidelines Network, *RCGP* Royal College of General Practitioners, *RACGP* The Royal Australian College of General Practitioners and *WHO* World Health Organization.

Appendix 6

Care of people who experience symptoms post-acute COVID-19

Source: https://covid19evidence.net.au/wp-content/uploads/FLOWCHART-11-CARE-OF-PEOPLE-WHO-EXPERIENCE-SYMPTOMS-POST-ACUTE-COVID19-V2.0.pdf?=210331-15213

CARE OF PEOPLE WHO EXPERIENCE SYMPTOMS POST ACUTE COVID-19

NATIONAL COVID-19 CLINICAL EVIDENCE TASKFORCE

LEGEND

EBR: Evidence-Based Recommendation
CBR: Consensus-Based Recommendation
PP: Practice Point

VERSION 2.0
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Background

People who have been infected with COVID-19 sometimes experience ongoing or new symptoms after the acute infection is over. [1-7] A range of symptoms have been reported in both adults and children, with variation in the duration of symptoms and clinical history. [1-7] For instance, symptoms may be experienced by people who had either mild or severe COVID-19. [2] Some symptoms may subside gradually with self-directed care alone, while other symptoms may require care from a health professional.

At present, there is no Australian or international definition for the combination of symptoms that a person may experience after an acute COVID-19 infection has resolved. As the evidence regarding these symptoms develops, so will our understanding of risk of the illness, clinical course and effective management approaches. However, many of the symptoms reported after an acute COVID-19 infection have common features with symptoms that are regularly managed in primary care and we can draw on current best-practice approaches to guide care.

The following recommendations provide guidance for the assessment and management of symptoms post acute COVID-19 infection. These recommendations will be updated as new evidence on the care of people with symptoms post acute COVID-19 emerges. **PP** [Taskforce]

Goals of Care

COMMUNICATION

Due to the broad range of effects post acute COVID-19, a biopsychosocial approach to care, within the local context, is important. Acknowledge the symptoms and offer information about the symptoms that they are experiencing, including management options. **PP** [Taskforce]

Rural and remote access to care

This flowchart should be applied after considering features of the individual, their preferences and the context in terms of rurality/remoteness, public health responses and proximity to rehabilitation or higher-level care. Transfer to a larger centre or the use of telehealth should be considered for those needing active rehabilitation. **PP** [Taskforce]

COORDINATED CARE

The general practitioner and primary health care nurse are well placed to coordinate person-centred care and they together should remain a central point in the care team. Other expertise in the care team may include: respiratory medicine, pulmonary rehabilitation, physiotherapy, sleep medicine, occupational therapy, social work, psychology, psychiatry, neurology, dermatology, cardiology, rheumatology, speech pathology, exercise physiology, nutrition and dietetics. This this could be accessed through community health, rehabilitation programs or post-COVID-19 clinics, where these are available. **PP** [Taskforce]

Use case conferences to facilitate coordinated care. **PP** [Taskforce]

Assessment

MANAGING RISK OF INFECTION

- Confirm all the criteria for release from isolation have been met for both the person and any others/associates presenting with them.
- Ensure appropriate personal protective equipment (PPE) is worn if:
  - the criteria for release from isolation have not been met;
  - there has been recent close contact with a confirmed positive case of COVID-19;
  - there are clinical symptoms suggestive of potential re-infection.

PP [NSW HealthPathway]

WHAT IS THE PROBABILITY DIAGNOSIS?

- Confirm that the person had COVID-19 (by checking that they had a PCR positive test), or is likely to have had COVID-19 (by checking that they have had symptoms consistent with a COVID-19 infection and/or known contact with a positive case or high risk setting). Document details of the acute illness.
- Check the current symptoms post acute COVID-19 and ask the person about their concerns, functioning and wishes in terms of their needs.
- Assess whether the current symptoms are likely to be related to acute COVID-19 infection.
- Assess whether the symptoms may be related to, or are exacerbated by, comorbid conditions. **PP** [Taskforce/ NSW HealthPathway]

ASSESSMENT OF RED FLAGS

Exclude red flag symptoms that could indicate the need for emergency assessment for serious complication of COVID-19. Red flag symptoms include severe, new onset, or worsening breathlessness or hypoxia, syncope, unexplained chest pain, palpitations or arrhythmias, new delirium, or focal neurological signs or symptoms. **PP** [NSW HealthPathway]

In some people, symptoms may indicate ongoing or worsening acute COVID-19. If goals of care include active disease management, please see recommendations for the treatment of COVID-19 in our living guidelines. **EBR** [Taskforce]

SYMPTOMS AND SIGNS THAT HAVE BEEN DESCRIBED POST ACUTE COVID-19

Investigate symptoms as per usual care. CBR[Taskforce].

The following symptoms and signs have been described by people post acute COVID-19 infection [1-7]:

Pulmonary symptoms
- Shortness of breath
- Cough

Neurological symptoms
- Fatigue
- Headache
- Cognitive dysfunction
- Sleep disturbance
- Loss of smell
- Paraesthesia

Psychological symptoms
- Anxiety
- Depression
- Mood swings
- Note that fatigue and sleep disturbance may also indicate the emergence of a mental health condition

Cardiac symptoms
- Chest pain

Musculoskeletal symptoms
- Non-specific pain
- Myalgia

Fever
- Low grade fevers

Reduced activity and functional level

Reduced nutritional status and weight loss

Post Intensive Care Syndrome
- Post Intensive Care Syndrome refers to one or more of the following symptoms that people experience following the receipt of care in an ICU. Symptoms may include anxiety, depression, cognitive impairment, memory loss, muscle weakness, dysphagia and reduced quality of life [8,9]

In some people, both adults and children, symptoms corresponding to a multisystem inflammatory syndrome [CDC 2021] have been reported. [7]

This list of symptoms and signs will be updated as new evidence emerges.

Management

- If red flags are present, arrange an emergency assessment of the patient in hospital. **PP** [Taskforce]
- Develop a management plan with the person addressing their main symptoms, problems, or risk factors, and an action plan. **PP** [Taskforce]
- Consider individual factors and access issues in determining location for further treatment or rehabilitation e.g. home-based, telehealth or face-to-face options. **PP** [Taskforce]
- At present, we do not have sufficient evidence to recommend specific interventions that are effective for managing symptoms post acute COVID-19 infections, therefore use clinical guidelines to manage symptoms and consider iatrogenic therapies. **PP** [Taskforce]
- Begin rehabilitation during the acute illness as appropriate. **PP** [Taskforce]
- Use local and regional protocols or health pathways to determine optimal referral pathways. **PP** [Taskforce]

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Appendix 7

Table 8. Evolving services for Long COVID patients (International)

Country	Services
UK	Long COVID clinics in the UK offering physical and psychological assessments for Long COVID patients that can be accessed through GP/healthcare professional referrals (NHS 2020). Post COVID Rehabilitation centre providing individualised rehabilitation services for long COVID patients (Survivor Corps 2021). *Your COVID Recovery* website is an open online platform where relevant resources related to COVID-19 recovery can be access (Rajan et al. 2021). Organisations: NHS Long COVID centers and The Wellington Hospital Rehabilitation Centre: Post COVID Rehabilitation
US	Post-COVID Recovery Clinic provides comprehensive health care for patients with Long COVID managed by a group of pulmonologist attached with satisfaction ratings (Temple Health 2021) Post-COVID-19 care centers in the US provide integrated and coordinated care pathways to Long COVID patients delivered by multidisciplinary care team (Survivor Corps 2021). Organisation: Iowa City University of Iowa Healthcare Respiratory Illness Follow-Up Clinic, Mount Sinai Center for Post-COVID Care etc
Germany	Post COVID outpatient clinics attached to large university hospitals provide patients consultation for Long COVID patients (Rajan et al. 2021) Organisations: Jena University Hospital/Hanover Medical School
Canada	Post COVID-19 Rehabilitation and Recovery Program provides face-to-face or virtual services specific for Long COVID patients delivered by a multidisciplinary team. They also provide holistic assessment and individualized rehabilitation program (Survivor Corps 2021). Rapid Access to Specialist Consultation is a service provided by internal medicine doctors to answer any urgent clinical questions from physicians and nurse practitioners who are handling patients recovering from COVID-19 (Survivor Corps 2021). Organisation: Providence Health Care: Post COVID-19 Recovery Clinic, Lifemark Health Group Post COVID-19 Rehabilitation and Recovery Program

India	Post COVID Care provides assessments , individualised care and rehabilitation from multidisciplinary team for Long COVID patients (Survivor Corps 2021) Organisations: Hospicio Post Covid Care Clinic, Majiwada Post-COVID Care Centre, etc
Ireland	COVID recovery outpatient service in Ireland (O'Brien et al. 2020)
Italy	Post COVID services providing rehabilitation services for patients who had prolonged stay in the ICU and chronic disabilities (Rajan et al. 2021). Organisations: AbilityAmo and San Raffaele Hospital in Lombardy Post-COVID-19 Day-Hospital structured a MDT and provides specialist assessments to patients with Long COVID (Rajan et al. 2021). Organisation: Fondazione Policlinico Agostino Gemelli
Czechia	Post-COVID Care Centre similar to earlier settings which offers MDT care for patients with Long COVID. Patients are managed by GP's with follow-up to pulmonary doctors (Rajan et al. 2021). Organisation: Hradec Králové teaching hospital

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